

**Antiretroviral treatment: Challenges experienced by HIV positive women in Zimbabwe**

Mini-dissertation

Submitted for the partial fulfilment of the requirements for the degree

Master of Social Work in Health Care

MSW (Health Care)

**By**

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**in the**

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February 2014

Pretoria

## ACKNOWLEDGEMENTS

The researcher would like to express her sincere gratitude and warm appreciation to the following people who in a way have contributed and inspired the researcher to finish the study:

My husband Tafadzwa, for always being patient, understanding, loving and supportive.

My two lovely daughters, Gamuchirai Nyasha and Michelle Tariro, for being my source of joy and this mini-dissertation is dedicated to you.

My late father, I dedicate this mini-dissertation in memory of you.

My grandmother, Mrs Jerita Kwanisai for being my inspiration.

My uncle and aunt, Professors Alexander Raphinos and Owence Chabaya for always being a source of support and encouraging me to achieve my goals throughout my years of study.

My in-laws, Rev and Dr Sungano and Gamuchirai Tsitsi Ndamba for their hospitality, support, encouragement and patience. I will never forget those night rides in Zimbabwe on bumpy and dusty roads coming from collecting the data to your home- thank you.

My family and friends, for giving me the perseverance and determination in order to finish this work. Your contributions are valuable.

Dr C.L. Carbonatto, my research supervisor, for sharing her immense knowledge, her valuable guidance, commitment and support. Her ideas helped me to put this mini-dissertation together to this final product.

The HIV positive women who participated in this study, for their time, opinions and assistance.

And above all, the Almighty God who made this mini-dissertation possible with his continued guidance, love and protection.



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### Declaration of originality

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Topic of dissertation:

**ANTIRETROVIRAL TREATMENT: CHALLENGES EXPERIENCED BY HIV POSITIVE WOMEN IN ZIMBABWE**

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## **ABSTRACT**

**Title: Antiretroviral treatment: Challenges experienced by HIV positive women in Zimbabwe.**

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**Degree: MSW (Health Care)**

**Supervisor: Dr C.L. Carbonatto**

HIV and AIDS which was discovered in the 1980s is causing havoc in many developing countries and Sub-Saharan continent is the hardest hit. Pratt (2008:8) highlights that “the number of people living with the disease is concentrated in the industrially developing world, mostly in those resource deprived countries least able to afford the care of HIV-infected people”. Zimbabwe is one of the SADC countries with the highest statistics of HIV and AIDS. Women account for the largest number of people infected by the pandemic and this could be as a result of the social and cultural norms which oppress women and their position in society.

Antiretrovirals (ARV's) are the life-long drugs given to HIV-infected people to slow the progression of the disease. There are different types of ARV regimens. Zimbabwe introduced the ART roll-out in 2004, however the ART users face multiple obstacles in accessing ARVs. The study targets women because they are a vulnerable group in society, specifically in Zimbabwe. Women have been subjected to stigma, discrimination, violence, humiliation, degradation and psychological torture when they are identified as being HIV positive. Some are neglected and deserted by their partners and families after disclosure, as a result many are too scared to disclose their status to families. The country's political and economic situation has a major impact on the HIV positive women's access to ARV treatment. This is compounded with the social and cultural norms and values of the people.

The focus of this study is on the challenges experienced by HIV positive women with regard to accessing ARV treatment in Zimbabwe. This study strived to understand the challenges HIV positive women encounter in adhering and accessing to ARV treatment. The goal was to explore the challenges experienced by HIV positive women with regard to accessing ARV treatment in Zimbabwe. The research question of the study was: What are the challenges experienced by HIV positive women with regard to accessing ARV treatment in Zimbabwe?

This study used a qualitative approach with a collective case study research design. The population for this study was the African women from Zimbabwe who were infected with HIV and AIDS. Non-probability purposive sampling was utilised in this study to select the sample of 10 women who were living with HIV and AIDS in Masvingo District, Zimbabwe and who were accessing ART. Specific criteria for sampling was used to select clients of two NGO's in Masvingo district of Zimbabwe: Batanai HIV and AIDS Service Organisation and the Reformed Church in Zimbabwe Community Based AIDS Program.

Semi-structured one-to-one interviews were used to collect data. The researcher sought permission of the participants to voice record their interviews and the researcher transcribed them personally. The data gathered was analysed and theme and sub-themes were generated from the data. The research findings were presented thereafter by providing a profile of research participants followed by thematic analysis of the themes and sub-themes from the transcriptions. Literature control and verbatim quotes were used to support these themes and sub-themes. The following are the themes from this study: Theme One- Information regarding HIV and AIDS, Theme Two- Information on ARV treatment, Theme Three- Societal and HIV positive women's views on HIV and AIDS, Theme Four- Experiences of being an HIV positive woman and Theme Five- Needs identified by HIV positive women.

The conclusions of this study reflect that HIV positive women experience some challenges in adhering and accessing ARV treatment. Disclosure, stigma and discrimination, traditional and faith healer's diagnosis of HIV and AIDS, access to medication for Opportunistic Infections, food shortage, distance to ARV sites, the availability and change of ARV regimens were amongst some of the factors which made access to ARV treatment a challenge.

Recommendations from this study can be used by HIV and AIDS stakeholders to understand the challenges and experiences by HIV positive women better. The social workers can also use the recommendations to find ways to make their services known to the communities and also improve their intervention and support to these women.

**KEY WORDS:**

*Antiretrovirals*

*Treatment*

*Challenges*

*HIV*

*AIDS*

*Women*

*Stigma*

*Discrimination*

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## CHAPTER 1

### GENERAL INTRODUCTION AND BACKGROUND OF THE STUDY

#### 1.1 INTRODUCTION

The HIV and AIDS epidemic which was discovered in the early 1980s is ravaging every aspect of people's lives. HIV (Human Immunodeficiency Virus) is a retrovirus that enters the body through the blood or the exchange of bodily fluids during sexual activity and may lead to the development of AIDS (Ross & Deverell, 2010:93; Longman Dictionary, 2003:772). HIV is the virus which enters the body through the exchange of bodily fluids during sexual activity or contact with the infected blood and destroys the body's immune system. AIDS (Acquired Immune Deficiency Syndrome) is a syndrome of opportunistic diseases, infections and certain cancers which cause the immune system to lose its efficacy and the infected person will die in the final stages of the disease (Ross & Deverell, 2010:91; Van Dyk, 2008:4). This is the progressive stage of HIV and is the end stage of the disease, whereby the body is unable to fight the infections due to the weakening of the immune system.

Globally, the populations affected by the HIV and AIDS pandemic are those that are socially and/or economically disadvantaged in terms of income, employment, culture, ethnicity and gender (Commonwealth Secretariat, 2002:4). The epidemic is threatening to wipe out decades of developmental gains because the disease targets the economically active group. Simmons (2012:9) states that "more than 70 percent of AIDS cases are found among adults between the ages of 20 and 49, the most economically and socially productive part of the population." HIV and AIDS have devastating effects mainly on women, because HIV affects women not only as individuals who are infected, but also negatively affects their multiple roles in the family and society at large. Pratt (2003:8) states that "the number of people living with the HIV disease is concentrated in the industrially developing world, mostly in those resource-deprived countries least able to afford the care for HIV- infected people." Sub-Saharan Africa, being the hardest hit by this pandemic, is faced with the biggest challenge ever to curb the spread of the disease due to political and economic constraints.

According to the UNAIDS (2004) as quoted in Amuyunzu-Nyamongo, Okeng'o, Wagura and Mwenzwa (2007:25), "Sub-Saharan Africa accounts for the highest prevalence of HIV, with most of those infected being women (57%)." Women account for the largest number of the pandemic and this could be as a result of social and cultural norms which subjugate women and also their position in society. Daulaire (2006:13) supports this idea by stating that "the faces of those newly infected with HIV/AIDS are more and more often the faces of women and girls. Women now account for nearly 60 percent of those infected with HIV in Sub-Saharan Africa." There is limited access to effective prophylactics, treatment of HIV- related opportunistic infections (OIs) and antiretroviral therapy (ART).

ARVs (antiretroviral drugs) are the medicines that fight HIV in one's body by suppressing the activity of a retrovirus (Page, Louw & Pakkiri, 2006:77; Southern Africa HIV and AIDS Information Dissemination Service, 2009:2). These are the drugs given to the person with HIV and AIDS to slow down the progression of the disease. Treatment is the use of medicines, surgery or psychotherapy to cure someone who is ill (Longman Dictionary, 2003:1771; Dictionary.com, [sa]:1). For the purpose of this study, treatment refers to the medication or clinical drugs used to improve the quality of life of a person with AIDS. This can be prophylactics and drugs used to treat OIs. Statistics revealed that 60% of women are living with HIV/AIDS in Sub-Saharan Africa (UNAIDS, 2010:25). Zimbabwe is amongst the troubled Sub-Saharan countries that are affected by HIV/AIDS.

The researcher searched for previous studies done on ARV treatment in Zimbabwe and it shows nothing has been done regarding the topic. Kambarami (2009) did a study on "the experiences of women of their HIV/AIDS status disclosure to sexual partners" whilst Nyoni (2008) looked at the "socio-cultural factors and practices that impede upon behavioral change of Zimbabwean women in an era of HIV/AIDS". Moyo (2009) also did a study on factors influencing the attendance of voluntary counselling and HIV testing amongst women. The above stated researchers were concentrating on the prevention aspects, but they did not look at the treatment aspect. It seems nothing or little has been done on ARV treatment and the challenges associated with it, hence the researcher is going to research the challenges and experiences faced by women with regards to accessing ARV treatment in Zimbabwe. The study is going to cover the gap in research on treatment and some challenges associated with it.

### **1.1.1 Theoretical Framework**

This study is from a theoretical framework of the Health Behaviour Theory making use of the biopsychosocial model which was first developed by George Engel in 1977 (Medpedia, 2009). This model takes note of the connectedness and the interdependence between the disease process, psychological and social functioning or dysfunctioning. Understanding the person's social, cultural and economic situation will ensure that she receives a comprehensive treatment. The biopsychosocial model believes that the physical problems and illness that people experience are caused by interaction between the biological, psychological and social factors (Weiten, 2004:521). This notion is supported by Scherger (2005:445) who describes the model as complex work that requires caring for the whole person and understanding how different aspects influence health. It takes a holistic approach, thus patients are to be seen as a whole socially, psychologically and physically. As the study is from the social work perspective, it will not focus on HIV and AIDS as a disease, but it looks at various factors which hinder the accessibility of ARV treatment for women. Factors such as culture, economic conditions, and individual and societal beliefs will be looked at, as well as the impact they have on ARV treatment.

### **1.1.2 Literature Review**

It has been reported that in Sub-Saharan Africa 12 100 000 women were living with HIV and AIDS out of 22 500 000 HIV positive people. In South Africa 3 300 000 women are living with HIV and AIDS out of 5 600 000 people living with the disease. Zimbabwean figures stand at 620 000 women out of 1 200 000 people living with HIV and AIDS, according to UNAIDS (2010), as cited by Sub-Saharan Africa HIV...([sa]:1). These were the only recent statistics that could be found in Zimbabwe and the figures are now most probably much higher.

Zimbabwe forms part of the Southern African Development Community countries (SADC) and it is one of the SADC countries with the highest number of HIV-infected people. Out of the 22 500 000 people in Sub-Saharan Africa living with HIV and AIDS 1 200 000 are Zimbabweans, as reported by UNAIDS (2010) as cited by Sub-Saharan Africa HIV...([sa]:1). Many people are struggling to make ends meet and there are some challenges which prevent them from adhering to the treatment. A challenge is something that tests strength, skill or ability and is especially stimulating to the person engaged in it (Longman Dictionary, 2003:242; Dictionary.com, sv 'World English Dictionary'). In relation to this study, challenges are the difficulties or problems encountered by HIV (positive women in accessing and adhering to

medication for their condition. These are the events or situations which an individual encounters in life and they will have an impact on the way he or she perceives life.

The country is eroded with a tense political and social climate; it is difficult to access and adhere to ARV treatment for the HIV and AIDS victims. According to HIV and AIDS...([sa]:10), “[t]he government has been increasingly hostile towards foreign non-governmental organizations (NGOs), to the extent where they threatened to pass a law that would give the government the power to interfere with how NGOs are run.” As a result of this hostility many countries have withdrawn their food and medical aid to the country. The prevailing economic and political situation in the country has motivated the researcher to conduct an investigation on the challenges experienced by HIV positive women with regard to ARV treatment in Zimbabwe.

The research targets women because they are a vulnerable group in society, specifically in Zimbabwe. Izumi (2006:1) propagates that “it is well-known fact that women and girls are especially vulnerable to infection.” The researcher aims to gain insight and knowledge on the experiences of her female counterparts with regards to accessing and adhering to treatment for HIV and AIDS, given a very good ARV treatment program set up by the government. The researcher is from Zimbabwe and she visits there regularly and is in contact with her family and professionals in the field. It is through this background that the researcher has observed the plight of women in Zimbabwe and would like to explore the challenges faced by HIV positive women in Zimbabwe in accessing and adhering to ARV treatment programs. The findings of the research may assist in improving services in the future with recommendations that may assist in the provision of HIV treatment to the marginalized groups in society. On a recent visit to Zimbabwe in May 2012, the need for such research was confirmed by professionals and healthcare workers from one of the NGOs, namely Mrs Mundawarara (2012) and Mr Marimi (2012) from Batanai HIV and AIDS Service Organisation.

Hall (2007:57) states that “the epidemic primarily affects the world’s poorest communities with greatest gender inequalities, disparities in income and access to productive resources, the marginalized, stigmatized and disempowered.” Women have been subjected to stigma, discrimination, violence and psychological torture when they are identified as being HIV positive. Many women are too scared to disclose their status to their families so as to avoid discrimination and stigmatization.

The challenges facing women with HIV in accessing and adhering to ARV treatment are numerous, including the distance between the ARV sites and where people reside, as well as the travelling costs. HIV and AIDS...([sa]:7) stipulates that “[women]... have to travel long distances to health centres in order to receive ARVs, which is another financial burden... a severe national shortage of healthcare workers has led to long waiting lists and administration problems.” The sites might also be too close, hence some women avoid going there for treatment for fear of disclosure and stigmatization, or the sites might be too far, which forces women to have to walk long distances, especially in rural areas. The physical distance patients have to travel to collect their medicines limit treatment access to HIV positive, women particularly in rural areas (UNAIDS, 2008:152; Heywood, 2004:266). Mundawarara (2012) is of the opinion that stigma is affecting HIV positive women’s access to ARV treatment, as some women have to look for bus fares and travel to the sites that are far away from where they live to get the treatment. When they arrive there they have to stand in long queues. Another challenge is the lack of a treatment buddy; it is very difficult for a woman with HIV and AIDS to ask someone she knows to accompany her to the ARV treatment site (Roets, 2011).

Poverty, lack of education and economic opportunities, especially in the developing countries, increase the vulnerability of women to HIV infection. According to Simmons (2012:12), “HIV/AIDS spreads faster under conditions of poverty, gender discrimination and economic insecurity and this is a lot for many Zimbabweans.” Women are not in charge of their bodies, they may not have the power to negotiate for safer sex due to social and economic power imbalances. Men initiate, dominate and are in control of sexual interactions and reproductive decision-making (Commonwealth Secretariat, 2002:26; Mahoro, 2005:6). Most women are submissive towards their husbands and if their husbands refuse to let them get treatment, they have to follow their orders. Sandasi and Cherewo (2006:2) reiterate that “[t]hey [women] are in no position to negotiate protected sex and therefore risk infection by not using condoms.” This is a big challenge faced by married women and women in stable relationships. From the presentation given by Mahoro (2005:7) on women, children and family treatment preparedness, it has been reported that in countries such as Zambia, negotiating condom use was difficult for rural women and it often resulted in gender violence. It is also difficult for women to convince their husbands to go for treatment and to negotiate safe sex, especially the use of condoms in the marriage.

Many women believe that if you are HIV positive you have to look thin; hence many women stop their treatment when they feel healthy and have picked up some weight (Roets, 2011). They think that they are cured and this is as a result of low literacy levels. The researcher agrees with the following viewpoint (Mahoro, 2005:25): “Treatment literacy is conducted in English and that limits access to information for women. It is also a limitation in accessing treatment.” Not all HIV positive women are literate. Marimi (2012) highlighted that due to staff shortages in the country, healthcare professionals do not have much time to give enough education to the HIV patients, hence many women with HIV and AIDS default their treatment. Factors such as the increasing external brain drain and weakness of the national medical education and training programmes contribute to the overall shortage of healthcare personnel (UNAIDS, 2008:154; Van Damme, Kober & Kegels, 2008:2110). Lack of education with regards to treatment is also another challenge experienced by women with HIV and AIDS in Zimbabwe.

The attitude of the healthcare workers is another challenge facing HIV positive women in getting treatment (Roets, 2011). The healthcare workers are suffering from burn out, they are overloaded with work and as a result they stigmatize people with HIV. Marimi (2012) propagates that the beliefs of women with HIV and AIDS is also another challenge with regard to antiretroviral treatment. Some women with HIV and AIDS consult with the traditional healers and faith healers and are forced or convinced to stop taking their treatment. This will lead to defaultment and instead they will use herbs and unclean water which will interfere with their health.

“Malnutrition has caused people living with HIV to develop AIDS faster, and is likely to have decreased the effectiveness of ARVs for those who are receiving treatment” (HIV and AIDS..., [sa]:8). Most women find it difficult to adhere to treatment due to lack of material needs such as food and money. Mahoro (2005:6) goes further stating that “one cannot talk about effective treatment without adequate nutrition, as treatment without proper nutrition can be counterproductive.” Marimi (2012) supports this idea by stating that 2011 was a poor season and even in 2012, many people are struggling to put food on their tables. Nutritional issues are a hindrance to ARV treatment. Mundawarara (2012) indicates that Masvingo is a drought prone region; nutrition is a problem in the area and even access to clean water is limited. Some areas cannot afford clean water and in areas where clean water is available, there is massive water cuts making it difficult for the HIV positive women to adhere to their treatment.

Maroleng (2005:9) highlights that “[o]nce robust, Zimbabwe’s economy has been devastated by bad policy decisions, mismanagement, corruption, and political instability.” There is political and economic instability in the country, compounded by abject poverty, erratic rains, and the deterioration of the health sector and food insecurity. These conditions make it difficult for HIV positive women to access and adhere to ARV treatment.

What is confusing is why HIV positive women are still experiencing some challenges in accessing and adhering to ARV treatment, while there is an ARV treatment programme running in the country. The prevalence of the HIV and AIDS pandemic has motivated the researcher to investigate the challenges faced by HIV positive women in accessing and adhering to ARV treatment. This may contribute to filling a gap of knowledge by drawing conclusions from the findings in a bid to improve the circumstances and supply of medication and also to educate women. The findings of the study may equip the healthcare workers with knowledge on how to help HIV positive women to develop or enhance their coping mechanisms and to develop effective support groups. The findings of this study may also broaden the knowledge base of social workers by developing knowledge and skills for social work practice in the area of HIV and AIDS management. It may assist to enhance ways in which social workers can help to curb and meet the challenges of HIV positive women in accessing and adhering to ARV treatment.

## **1.2 PROBLEM FORMULATION**

The number of people affected by the HIV and AIDS pandemic in Southern Africa is very high and according to UNAIDS (2009), over two thirds (67%) of the people were living with HIV in the continent and nearly 2 million deaths were AIDS related in 2008. The situation is worse in Zimbabwe because of poverty, the collapsing medical health system and political instability. Women are at the centre of the world’s concern as far as HIV and AIDS are concerned, as the epidemic wave has affected millions of women (Pratt, 2003:194). The main problem is that HIV/AIDS is incurable and has troubled many nations, as it affects mostly the economically active population.

In September 2005, the United Nations General Assembly set a target which aimed to ensure the universal access to treatment by 2010 (Global Access to HIV..., 2006:176). This treatment target seems to be failing in Zimbabwe; on a recent trip to Zimbabwe the researcher observed that people are having difficulties in accessing HIV treatment. The background discussed above

reveals that women still experience some challenges in accessing ARV treatment, particularly in Masvingo, Zimbabwe. “One study found that Zimbabweans on the government free ARV programme, are often expected to pay bribes for drugs and services that are supposed to be for free under the programme” (HIV and AIDS...[sa]:8). The majority of people living with HIV are poverty stricken and are suffering, because the treatment can only be afforded by the elite people who can pay bribes to get the drugs.

White and Carr (2005), as quoted by UNAIDS (2008:77), state that “[f]ear of stigma and discrimination also makes people living with HIV less likely to seek care and treatment, adhere to treatment, and disclose their HIV status to their sexual partners.” Women specifically experience more challenges in accessing and adhering to ARV treatment than men, because they are not keen to disclose their status for fear of stigma and discrimination, lack of financial and emotional support from their partners or families, as well as abject poverty. Many women are dependent on their partners for money for transport in order to access healthcare facilities, medication and diagnostics, among other things (Mahoro, 2005:6). Particularly in Zimbabwe, due to political instability and lack of resources, there are only a few ARV treatment sites. Thus people face challenges in getting to the treatment sites; they are far away, which means they need to commute or walk long distances, and for the ones that are nearby stigmatization is a problem. Healthcare facilities might be far away with HIV positive women having to travel long distances with inadequate transport or funding for transport (Training Manual..., 2005:21). Women in Zimbabwe, due to their poor socio-economic situation, face malnutrition as well as a lack of financial, emotional and psychological support from their families.

Price-Smith and Daly (2004:24) state that “[g]overnance in Zimbabwe, already exhibiting considerable potential violence and institutional instability, likely will worsen further as a result of the HIV/AIDS epidemic.” The researcher, in her networking with social workers and organizations in the country, has observed that the economic and political situation in the country has crippled the health system. In Zimbabwe, women are a vulnerable group and they are struggling to make ends meet. In 2009, currencies such as the Botswana pula, South African rand and the US dollar were allowed to be used locally and that ended hyperinflation and restored price stability (Zimbabwe Economy Profile, [sa]:1). It is very difficult to get hold of the US dollar, which is the country’s unofficial currency. The researcher has also noticed that stigma, poverty, lack of support from spouses and family, malnutrition, and distances travelled

to get medication are some of the challenges encountered by women with HIV and AIDS in Zimbabwe.

It is against this background that the researcher has decided to focus this study on the challenges experienced by HIV positive women with regard to accessing ARV treatment. There is definitely a gap in literature and research regarding HIV and AIDS in Zimbabwe, because of the political and economic situation over a number of years. There has not been any research on the subject and Zimbabwe is one of the most affected countries, where in-depth research needs to be done regarding the challenges experienced by HIV positive people accessing ARV treatment.

The focus of this study will therefore be to explore the challenges experienced by HIV positive women with regard to accessing ARV treatment in a certain district of Zimbabwe, from which a sample will be drawn, namely Masvingo.

### **1.3 GOAL AND OBJECTIVES OF THE STUDY**

#### **1.3.1 Goal of the Study**

- ❖ To explore the challenges experienced by HIV positive women with regard to accessing ARV treatment in Zimbabwe.

#### **1.3.2 Objectives of the Study**

- ❖ To describe the phenomenon of HIV and AIDS in Southern Africa and specifically in Zimbabwe, the position of HIV positive women as a vulnerable group in society, and ARV treatment.
- ❖ To explore the challenges experienced by women with HIV and AIDS in Zimbabwe.
- ❖ To explore the challenges of HIV positive women in accessing and adhering to ARV treatment in Zimbabwe.
- ❖ To make recommendations for improving services in Zimbabwe.

## 1.4 RESEARCH QUESTION

“A research question is a logical statement that progresses from what is known or believed to be true to that which is unknown and requires validation” (Lipowski, 2008:3). The research question thus guides the researcher throughout the research process on what information is required, the research approach and design to be used; hence it has to be clear. In this study the researcher wants to determine what challenges are experienced by HIV positive women in Zimbabwe on ARVs. This study is qualitative, thus the research question will be as follows:

**What are the challenges experienced by HIV positive women with regard to antiretroviral treatment in Zimbabwe?**

## 1.5 RESEARCH METHODOLOGY

### 1.5.1 Research Approach

The study adopted a qualitative research approach in order to get responses from women with HIV and AIDS, which was often not disclosed, with regard to the challenges and experiences they faced in accessing and adhering to ARV treatment, which is a sensitive topic. Fouché and Delport (2011:65) reiterate that “[t]he qualitative research paradigm in its broadest sense refers to research that elicits participant accounts of meaning, experience and perceptions. It also produces descriptive data in the participant’s own written or spoken words.” The approach mainly focuses on meaning, language and cultural experiences in social contexts and is mainly concerned about understanding particular situations rather than generalizing findings (Du Plooy, 2011:136). This approach was useful for the study, because it allowed the researcher the opportunity to gather rich data on a sensitive topic as it was revealed by the participants and also to have personal contact with the participants. A collective case design was used and data was gathered by means of one-on-one interviews using an interview schedule. Purposive sampling was used to select the participants. The interviews were voice recorded and transcribed by researcher. The research methods will be discussed in Chapter 3 in detail, together with the ethical considerations of the study.

## 1.6 LIMITATIONS OF THE STUDY

- Negotiating for study leave with the researcher's employer was a challenge, as well as having to travel to Zimbabwe to conduct the study.
- Travelling to the rural areas on the dusty and bumpy roads and back at night was nerve wrecking and challenging.
- Getting participants was a problem, especially those below the age of 29, as they were not enthusiastic to partake in the study due to the sensitive topic.
- Some of the HIV positive women wanted to be guaranteed payment for their participation in the research, hence it took some time to get the participants to take part in the study voluntarily without payment.

## 1.7 CONTENTS OF THE RESEARCH REPORT

**Chapter 1:** The general introduction and background of the study.

**Chapter 2:** A literature review regarding women living with HIV and AIDS in Sub-Saharan and Southern Africa and the challenges in accessing ARV treatment.

**Chapter 3:** Research methodology and research findings.

**Chapter 4:** Summary, conclusions and recommendations from the study.

## **CHAPTER 2**

# **A LITERATURE REVIEW REGARDING WOMEN LIVING WITH HIV AND AIDS IN SUB-SAHARAN AND SOUTHERN AFRICA AND THE CHALLENGES IN ACCESSING ARV TREATMENT**

### **2.1 INTRODUCTION**

The goal of the study is to explore the challenges experienced by HIV positive women with regard to accessing ARV treatment in Zimbabwe. This chapter focuses on the theoretical framework of this study, plus a literature review that is centred mainly on the phenomenon of HIV and AIDS and ARV treatment.

Globally, the populations affected by the HIV and AIDS pandemic are those that are socially and/or economically disadvantaged in terms of income, employment, culture, ethnicity and gender (Commonwealth Secretariat, 2002:4). The epidemic is threatening to wipe out decades of developmental gains because the disease targets the economically active group. Pratt (2003:8) states that “the number of people living with the HIV disease is concentrated in the industrially developing world, mostly in those resource-deprived countries least able to afford the care for HIV- infected people.” Sub-Saharan Africa, being the hardest hit by this pandemic, is faced with the biggest challenge ever. That is to curb the spread of the disease, which is further complicated by political and economic constraints.

ARVs are the drugs given to the person with HIV and AIDS to slow down the progression of the disease. Meticulous adherence to ARV treatment is vital for the ART to be effective. There are various factors which affect adherence such as poverty, alternative disease constructs, stigma, gender and unpredictable drug supply (Karim & Karim, 2010:503). These challenges and others are going to be discussed in detail in this chapter.

### **2.2 THEORITICAL FRAMEWORK**

Munro, Lewin, Swart and Volmink (2007:104) state that “[t]heories may assist in the design of behaviour change interventions in various ways, by promoting and understanding health

behaviour, directing research and facilitating transferability of an intervention from one health issue, geographical area or healthcare setting to another.” Theories and models help us to understand people’s behaviours and they are based on concepts. Nyoni (2008:30) goes further stating that “[t]heories and concepts play a critical role in any social science research in generating ideas, formulating and evaluating hypothesis and building new theories.” The theory of Health Behaviour has been used in this study to identify the challenges experienced by HIV positive women in accessing antiretroviral treatment and to come up with the study’s conceptual framework. In this context the Health Behaviour Theory helps us to understand why HIV positive women in Zimbabwe fail to adhere to ARV treatment.

### **2.2.1 Health Behaviour Theory**

Health behaviours are the actions we engage in with the aim of maintaining, attaining or regaining good health or in order to protect against illness (Rodham, 2010:3). It encompasses all the things we do which influence our physical, mental, emotional, psychological and spiritual selves. There are two types of health behaviours: there are those that increase the risk of illness and those that promote health (French, Vedhara, Kaptein & Weinman, 2010:17). This implies that there are positive health behaviours and risky health behaviours. A number of factors influence the type of behaviours which we engage in, whether it is helpful or harmful to our health. In this instance the positive health behaviour for HIV positive women is taking ARV treatment religiously, exercising and following a good diet. The risky behaviour is defaulting treatment, unsafe sex, drinking and living unhealthy lifestyles.

French et al. (2010:18) highlight that positive health behaviours are those “activities that may help to prevent disease, detect disease and disability in an early stage, promote and enhance health, or protect from risk or injury.” Much of health behaviours are performed by people with a diagnosed condition and are aimed at delaying the future progression of the disease (French et al., 2010:18). HIV positive people take ARV treatment in order to slow down the progression of the virus.

There are many factors which influence health behaviour factors such as sociocultural, environmental, demographic, microeconomics, system of provision of services, health service, psychological and biological (French et al., 2010:28; Ryan & Carr, 2010:67). Culture, socio-economic status, treatment availability and societal attitude to treatment are some of the factors which can promote or hinder HIV positive women from taking their ARV treatment. French et

al. (2010:29) went on stating that “[h]ealth behaviours are determined by a range of personal and socio-economic factors, and need to be understood within the broad context of people’s lives.” The economic and political situation in Zimbabwe has a major impact on the accessibility of ARV treatment for HIV positive women.

Within the Health Behaviour Theory, theories have been developed at a variety of levels such as the individual, interpersonal, group, organizational and community levels (Noar & Zimmerman, 2005:276). These theories and models were developed to predict and explain behaviour (Ryan & Carr, 2010:67).

### ***2.2.1.1 Biopsychosocial model***

This study is going to apply a model which is a model within the Health Behaviour Theory, namely the biopsychosocial model (BPSM). The biopsychosocial model was first developed by George Engel in 1977 (Medpedia, 2009). This model takes note of the connectedness and the interdependence between the disease process, and psychological and social functioning or dysfunctioning. Every person seeking medical attention must be seen as possessing biological, psychological and social dimensions which are in constant and continuous interaction with each other (Spies, 2007:158). Understanding the person’s social, cultural and economic situation will ensure that he/she receives a comprehensive treatment. The researcher agrees with the following view: “Adopting a biopsychosocial model of care ensures all factors influencing the patient’s ability to manage and cope with their condition can be identified, and where possible, addressed” (Ryan & Carr, 2010:64). Spies (2007:158) supports this notion by stating that this model is important in treating the patient as a whole. With all aspects that are relevant to his/her situation taken into consideration. This model takes a holistic approach to care and treatment.

- **Biological**

The biological or physical aspect encompasses the individual’s body, including the complexity of the various systems and organs within the human body. Sarafino (2006:13) sees the biological system as a complex system of genetics, functions and structures of the human physiology. The different systems of the human body influence each other. “The symptoms of HIV and AIDS are the biological aspects” (Spies, 2007:162). When HIV strikes the body, it has an effect on the entire human experience. It affects one’s family and work environment, and how these systems react

have an influence on how one handles one's illness. Regarding the biological dimension, Spies (2007:162) identified certain aspects to be assessed in adherence and access to ARV treatment such as gender, age, medical history, CD4 count and viral load, side effects, symptoms, opportunistic infections and general appearance. The personal beliefs of HIV positive women influence how they view illness and their personal history will show that they acquired skills for coping with illness.

The idea of interactions are increased by the research done by Garland and Howard (2009:191) which states that experiences can lead to change, even at a neurobiological level. But Taylor and Field (2003:56) go further in making the link between the social and biological by stating that a person's past social position is a marker for a person's current biological status. The way in which HIV positive women view their condition has an influence on their adherence to ARV treatment.

- **Psychological**

Kaplan et al. (1994), as cited in Spies (2007:164), highlight that “[t]he psychological dimension emphasizes the effects of psychodynamic factors, motivation and personality on the experience of illness and the reaction to it.” The psychological aspect encompasses the person's mind or thoughts. Sarafino (2006:13) believes that psychology consists of cognition, emotion and motivation. Psychology influences health in the way people perceive and think about health and illness. Sarafino (2006:13) sees cognition as perceiving, learning, recall, thoughts, interpreting and believing. A person's thoughts and beliefs influence his life, well-being and ultimately his/her health. The following psychological matters identified by Spies (2007:164) affect adherence positive or negatively: personality, feelings, emotions and emotional stressors, attitudes towards medical care, health and illness, health beliefs, fear, and motivation or lack of motivation. The way HIV positive women perceive their condition influences their access to ARV treatment.

- **Social**

The social aspect encompasses the groups and settings that the individual belongs to and comes in contact with. This includes the society, community and family. Spies (2007:166) highlights that “[t]he social environment refers to the quality and

characteristics of one's situation, including interpersonal relationships, resources for meeting one's needs and one's position, roles and participation in the society." Sarafino (2006:14) goes further stating that the community environment has a great influence on the person's health. Their influence on a person is the greatest and according to Sarafino (2006:14), they are the people who can motivate someone to change their habits. Stigma and discrimination from the community has a greater influence on the accessibility of ARV treatment to HIV positive women. Spies (2007:167) identified the following social and environment matters that affect adherence: accommodation – rural, urban; relationships – familial, support systems, marital status, sexual matters, disclosure, social stability; literacy – knowledge, education; socio-economic status; nutrition; ethnic, cultural and religious beliefs.

- **Spiritual**

The spiritual aspect is a new component to the biopsychosocial model and is not necessarily seen as part of the model by all academics. Van Wormer and Davis (2008:12) believe that the spiritual aspect is a key to the healing process within health. A person's belief is something greater, gives hope to seek treatment and stay positive in the face of adversity. Carr (2004:24) supports this by stating that a belief system or religion helps people find hope. He goes even further by stating that being involved in a religion leads to a physically and psychologically healthy lifestyle. Culture has a great impact on a person's belief about illness (Sarafino, 2006:242). Culture influences the behaviour of people; it plays a pivotal role in determining what people do and how they do it (Nyoni, 2008:75). The belief system of HIV positive women has an impact on their access to ARV treatment.

Culture and religion can include practices and beliefs that promote health and affect the cause and outcome of disease (Sarafino, 2006:241). Within the Zimbabwean context, culture is very important to many communities and influences people's perspective on health and treatment. Nyoni (2008:93) propagates that "Zimbabwe is a multi-religious society with Christianity, African Traditional Religion and Islam as the chief religions practiced in the Southern African country." The spirituality of HIV positive women is a key aspect and can influence their access and adherence to ARV treatment.

The biopsychosocial model propounds that the physical problems and illness that people experience are caused by interaction between the biological, psychological and social factors (Weiten, 2004:521). This notion is supported by Scherger (2005:445) who describes the model as complex work that requires caring for the whole person and understanding how different aspects influence health. It takes a holistic approach, thus patients are to be seen as a whole socially, psychologically and physically. The adoption of the biopsychosocial model in ART settings will provide an opportunity for the patients' feelings and perceptions regarding their biological state to be attended to, thereby improving their coping capacity and adherence (Spies, 2007:163). The BPSM model was chosen to guide the study's conceptual framework and has been modified to include the socio-demographic, cultural and psychological factors that are relevant to Africa, in particular Zimbabwe.

The social theory propounds that HIV transmission, prevention and treatment is a complex issue that cannot be explained by focusing on the individual's psychological and cognitive theory alone. Societal norms, religious beliefs and gender power relations ascribe meaning to the person's behaviour and enable either positive or negative behaviour change (van Dyk, 2012:145). As the study is from the social work perspective it will not focus on HIV and AIDS as a disease, but it looks at various factors which hinder the accessibility of ARV treatment for women. Factors such as culture, economic conditions, and individual and societal beliefs will be looked at, as well as their impact on ARV treatment.

## **2.3 ZIMBABWE'S SOCIAL, CULTURAL, POLITICAL AND ECONOMIC SITUATION.**

### **2.3.1 Socio-Cultural Aspect**

The Zimbabwean society is patriarchal in nature, emanating from the socialization process. Men are in control of all sexual and non-sexual relationships and decision making is mainly in their hands, thereby placing women in suppressed positions (Nyoni, 2008:76; Sandasi & Cherewo, 2006:1). Mahoro (2005:25) supports this notion by stating that women need their husbands' consent on any decisions, even in those that affect their bodies such as access to treatment, and if the husband says no his word is final and the woman has to obey it. UNICEF (1999), as cited in Nyoni (2008:75), goes further stating that "[I]like the majority of developing countries, Zimbabwe is a culturally society. This is to say people's instincts and thought processes are not influenced by cultural nuances, but that culture is reverted to and embraced

in situations that are unfamiliar to duty bearers or where in times of crisis no contemporary solutions can be found.” To understand the individual, one has to understand the cultural forces that influence his/her behaviour. Culture has an impact on women’s access to ARV treatment.

Riphenburg (1997:34) stipulates that “[t]he traditional structure of the Zimbabwean family makes it difficult for women to obtain the authority and resources they need during times of economic strain.” A Zimbabwean woman is in most cases under the custody of a male authority, either her father, partner and/or husband to whom she is subordinated (Nyoni, 2008:76). Women are expected to respect and listen to male figures in their lives. Nyoni (2008:76) goes further highlighting that “the societal environment in Zimbabwe is one, which degrades and devalues the women’s social worth making them unable to seek and enjoy good health.” Marriage is seen as an ultimate career for women and society views divorced or unmarried women as social failures and as a result many women are pressured to marry and to stay in abusive and unhealthy marriages to avoid embarrassment (Riphenburg, 1997:35). Certain cultural practices, such as widow inheritance, appeasing of vengeful spirits and the douching of the vagina to make it tight, pose dangers to the health of women (Nyoni, 2008:98; Sandasi & Cherewo, 2006:3). Certain cultural practices and expectations have an impact on the women’s access to ARV treatment.

### **2.3.2 Political Aspect**

Zimbabwe was colonized by Britain, but gained its independence in 1980. Since the country attained independence in 1980 it has been ruled by one party, ZANU-PF, led by President Robert Mugabe (Maroleng, 2005:7; HIV and AIDS..., [sa]:3). It has been reported that “Mugabe’s rule has been marked by corruption, human rights abuses and media suppression, all of which have had an impact on the AIDS epidemic” (HIV and AIDS..., [sa]:3). Mugabe’s rule has been seriously challenged by a viable political opposition, a vibrant civil society and by international leaders (Petrovic, 2012:1; HIV and AIDS..., [sa]:3). Despite attaining independence, the Zimbabwean political arena faced a lot of criticism and this also had an impact on HIV and AIDS and ARV treatment, because many international donors withdrew their aid from the country.

There was a great disparity between the quality of land owned by the black and white Zimbabwean farmers. The government introduced the Land Reform Programme in 1999 and it began to forcibly evict white farmers from their land (Africa Economic Development

Institute, 2009:1; HIV and AIDS..., [sa]:3). This led to the deterioration of economy, increased poverty and reduced access to education and healthcare (HIV and AIDS..., [sa]:3). Operation Murambatsvina (Restore Order) followed in May 2005 in all urban areas in which many houses and businesses were demolished and tenants were forcibly removed, leaving hundreds of thousands of people homeless, unemployed and starving with no access to food, water, sanitation or healthcare (HIV and AIDS..., [sa]:3; Maroleng, 2005:3). HIV positive people were affected by the operation because they were displaced and left with no access to ARV treatment. By July 2005, it was estimated that operation Murambatsvina displaced over 79500 adults living with HIV. These individuals were receiving ARVs, but they no longer had access to them as treatment centres and clinics had been demolished (HIV and AIDS..., [sa]:4). HIV positive people are still facing the same challenge of accessing treatment because some of them have moved to rural areas where the healthcare facilities are few and often located far away from where they are staying.

Credible opposition to ZANU-PF emerged in the early 1990s under conditions of poverty, unemployment and public concern about presidential powers (Maroleng, 2005:7). Currently there are many political parties in Zimbabwe. Tinho (2013:1) mentions that “[o]n 15 September 2008, President Robert Mugabe was forced into a political union with a bitter rival: Morgan Tsvangirai of the Movement for Democratic Change (MDC-T). This move culminated in the Global Political Arrangement (GPA) the foundation of the current coalition government of ZANU-PF, MDC-T and the smaller MDC faction MDC-M.” Despite the coalition government, Zimbabwean politics is still unstable. Petrovic (2012:1) supports this idea by stating that “...Zimbabwe was consistently ranked as a ‘Not Free’ country, at one point, even reaching the infamous status as one of Freedom House’s ‘worst of the worst’ countries.” The sense of hopelessness and despair among Zimbabwean citizens is magnified by the socio-political instability experienced in the country coupled with rising levels of mortality and morbidity resulting from HIV and AIDS (Price-Smith & Daly, 2004:25). There is continued suppression of fundamental democratic principles such as freedom of speech and expression, press, information and of public assembly (Price-Smith & Daly, 2004:25; Human Rights Watch, 2012:3). HIV positive women are caught up in the web of politics; they cannot voice their concerns regarding the challenges they experience with regards to access to ARV treatment.

Leaders of the SADC intervened demanding an end to political violence and arbitrary arrest, calling for adherence to their drafted electoral road map that would lead to free, fair and

credible elections (Human Rights Watch, 2012:4). The parliament has adopted the new constitutional referendum which was voted for on the 16<sup>th</sup> of March 2013 (Tinh, 2013:1). It has been speculated that the national elections are going to be held later in 2013. The prevailing tense political situation in the country could have an impact on HIV positive individuals' access to ARV treatment, especially women, which this study wishes to explore.

### **2.3.3 Economic Aspect**

Zimbabwe experienced economic melt-down for more than a decade, but now it is recovering. Zimbabwe's inclusive government has made progress in improving the economic situation of the country (Human Rights Watch, 2012:1). The political economic crisis which has unfolded in the past decade has resulted in two-digit negative growth rates, sky-rocketing inflation, decline in the rule of law and a disintegration of markets (Dekker, 2009:1). Infrastructure and regulatory deficiencies, on-going indigenization pressure, policy uncertainty, a large external debt and insufficient formal employment are some of the difficult economic problems the country is experiencing (Zimbabwe Economy Profile, 2012:1). Despite the Government of National Unity, the country is reeling from financial problems. Njikazana (2013:1) goes further quoting a statement made by the Finance Minister of Zimbabwe, Mr Tendai Biti, stating: "Last week when we paid civil servants there was US\$217 (left) in government coffers', Biti told journalists in the capital of Harare, claiming some of them had healthier bank balances than the state." This alone shows the state of the country's economy and it has an impact on the ARV treatment and access.

Zimbabwe used to be a bread basket of Africa but now it relies on food imports from other countries. The researcher agrees with the following view (Clemens and Moss, 2005:1): "Zimbabwe, once a vibrant and diversifies economy had been a hope for Africa's future. Today, it is a country in deep crisis and the signs of collapse are everywhere." Agriculture was the backbone of the country's economy. The government introduced the Land Reform Programme in 2000 which aimed at redistributing the land from the white to the black farmers and it was characterized by chaos and violence (Africa Economic Development Institute, 2009:1; Zimbabwe Economy Profile, 2012:1). The program damaged the commercial farming sector and it turned Zimbabwe into a net importer of food products (Zimbabwe Economy Profile, 2012:1). Zimbabwean farming activity has been greatly affected by the Land Reform Programme and this seems to have an impact on the women's access to ARV treatment.

The Zimbabwean dollar is no longer in use and people are using currencies of other countries. Africa Economic Development Institute (2009:2) mentions that “[b]ecause of the hyperinflation, the largest denomination on the former Zimbabwean dollars was not able to buy a loaf of bread.” The official rate of inflation increased from 15% in 1990, to 22,5% in 1995, 58,5% in 2000, 525% in 2003, and finally to nearly 8 000% in August 2007 and 231 000 000% in 2008 (Africa Economic Development Institute, 2009:2; Dekker, 2009:1). In early 2009, the Parliament accepted the use of foreign currency into all businesses; currencies such as the Botswana pula, South African rand and the US dollar are used locally (Africa Economic Development Institute, 2009:2; Zimbabwe Economy Profile, 2012:1). In many cases women are financially dependent on men for food, transport, drugs and diagnostics (Mahoro, 2005:22) and with the soaring economic situation in the country, some HIV positive women encounter some challenges in accessing ARV treatment. On a brighter side the Zimbabwean economy is improving slowly. It has been reported that US\$3,8 billion has been projected to be the government’s national budget for 2013 and the economy is projected to grow with 5.0% (Njikazana, 2013: 2). There is light at the end of the tunnel, as the improvement of the economy will also have a positive impact on the accessibility of ARV treatment to HIV positive citizens.

## **2.4 HIV AND AIDS PREVALENCE AND EPIDEMIOLOGY IN SOUTHERN AFRICA AND IN ZIMBABWE**

### **2.4.1 Sub-Saharan Africa**

HIV and AIDS was discovered in the early 1980s and is spreading like a veld fire, especially in developing countries. Southern Africa, of which Zimbabwe is part, is the epicentre of the HIV and AIDS epidemic and the countries within that region register the highest HIV and AIDS prevalence rate in the world (Suitcliffe, van Dijk, Bolton, Persaud & Moss, 2008:477; Zimbabwe National HIV..., 2006:1). UNAIDS (2008:30) mentions the following: “Sub-Saharan Africa remains the region most heavily affected by HIV, accounts for 67% of all people living with HIV and for 75% AIDS deaths in 2007.” This notion is supported by the Global Health Council (2009:205) which states that Sub-Saharan Africa makes up 10% of the world’s population and approximately two-thirds of people living with HIV world-wide also live in this region. The figures of the epidemic are alarming.

HIV/AIDS has become an added burden on an already strained healthcare system in Sub-Saharan Africa and it is the leading cause of illness and death (Karim & Karim, 2010:359).

Regarding the severity of HIV and AIDS in the region, van Dyk (2012:7) mentions that “Southern Africa remains the area most heavily affected by the epidemic and it is host to nine countries with the highest HIV prevalence in the world including Swaziland (25,9%), Botswana (25%), Lesotho (14,3%), Zimbabwe (18,1%), South Africa (16,9%), Zambia (14,3%) and Malawi (12,7%).” Rates of HIV and AIDS have been reduced in some parts of the world, but the epidemic continues to evolve in a catastrophic fashion in Sub-Saharan region.

It has been reported that in Sub-Saharan Africa 12 100 000 women were living with HIV and AIDS out of 22 500 000 HIV positive people. In South Africa 3 300 000 women are living with HIV and AIDS out of 5 600 000 people living with the pandemic. Zimbabwean figures stand at 620 000 women out of 1 200 000 people living with HIV and AIDS, according to UNAIDS (2010) as cited by Sub-Saharan Africa HIV...([sa]:1). The epidemic particularly affects poor regions and it is linked to poverty and the severity of its impact means that is not only a health problem, but also a development problem (Yamamori, Dageforde & Brune, 2003:12). Many young people are infected with the disease. Rupiya (2006:163) highlights that women and young girls in particular are at a greater risk of contracting the disease giving particular reference to Zimbabwe and other African countries. This idea is supported by Simmons (2012:9) who states that the “current peak ages for the disease are 20-29 for women and 30-39 for men, reflecting the trend throughout much of Africa where women became infected with HIV at a younger age than their male counterparts.” This can be attributed to gender imbalance and economic dependency on the part of women.

The researcher agrees with the following view: “HIV is highest among economically productive adults of child-bearing age and has enormous impact on families, communities and regional economies” (Campbell, Scott, Madanhire, Nyamukapa & Gregson, 2011:176). Simmons (2012:9) reiterates that “more than 70 percent of AIDS cases are found among adults between the ages of 20-49, the most economically and socially productive part of the population.” HIV and AIDS have a ripple effect; it affects people socially and psychologically and its consequences are very hard to bear at a family, community and national level. Women and girls are more often infected with HIV and AIDS and they account for 60% of HIV infections in the world (UNAIDS, 2008:33; Daulaire, 2006:13). Women account for the largest number of people affected by the pandemic and this could be as a result of social and cultural norms which subjugate women and also their position in the society.

## 2.4.2 Zimbabwe

HIV and AIDS cases were identified in Zimbabwe in 1985. Zimbabwe forms part of the Southern African Development Community countries (SADC). In the past, Zimbabwe had a high prevalence rate of the epidemic and was ranked in the 3<sup>rd</sup> position in Southern Africa with 1,2 million people living with HIV (Fraser, Ruark, Gorgens, James, Milanzi, Calvin, Ibbesson, Mpofu, Nzima, Mpofu & Yekeye, 2010:28). Simmons (2012:9) supports this notion by stating that “[a]long with South Africa and Botswana, Zimbabwe has been identified by UNAIDS as a country with one of the highest prevalence rate of adults living with HIV. For every five adults, it is estimated that one is infected with it.” The Zimbabwean Ministry of Health and Child Welfare (2012:1) asserts that Zimbabwe has a projected population of 12,7 million. It further reports that 1 159 097 adults and children were estimated to be living with HIV and AIDS in 2011 and 597 293 adults and children were in urgent need of ARVs by the end of the year. The number of people who need ARV treatment is increasing every year thereby overwhelming the already struggling healthcare system.

In 2002, the government of Zimbabwe declared HIV and AIDS a national emergency (Zimbabwe National HIV..., 2006:1). The reduction of HIV and AIDS prevalence is especially striking in Zimbabwe (UNAIDS, 2008:39). Zimbabwe National HIV... (2006:9) supports this idea by stating that “[t]he overall HIV prevalence in the Zimbabwe adult population has decreased from estimated 24,1% in 2003 to an estimated 20,1% in 2005 of the adult population (ages 15-49).” This shows that many people are now aware of the epidemic and are taking action to prevent it. The pandemic has adverse effects on individuals, families, household, communities, business and the economy.

It is the women and children who are heavily infected with the disease (Van Dyk, 2012:8). Zimbabwe National HIV... (2006:5) propagates that “[f]ifty-five percent of those known to be infected by the virus are women.” Many women are at the receiving end of the disease and societal norms and culture make it difficult for them to emancipate themselves from the shackles of the disease. Harries, Zachariah, van Oosterhoet, Reid, Hosseinipair, Arendt, Chirwa, John, Schaiten & Kamoto (2010:60) assert that “hope and optimism have slowly but steadily begin to replace despair and death in those countries and areas most affected by HIV/AIDS epidemic.” The introduction of ARVs has made life easier for people living with HIV and it brought hope to the already dejected people. ARVs slow the progression of HIV and AIDS and it improves one’s quality of life. Many public hospitals and clinics are

overcrowded with the increasing number of HIV positive people needing ARV treatment. The increased use of ART in Zimbabwe has been a success story in the country.

## 2.5 ANTIRETROVIRAL TREATMENT (ART)

HIV and AIDS has no cure, however there are drugs called antiretroviral drugs (ARVs) which are used for the treatment of HIV and AIDS. ARVs do not cure AIDS but they do reduce the mortality and morbidity rate, thereby improving the quality of lifestyle of those infected (Yamamori et al., 2003:212). Karim and Karim (2010:529) support this notion by stating that the main aim of ART is to delay or prevent the progression to AIDS and death of HIV infected patients.

Van Dyk (2012:22) states the goals of ART as follows:

1. ***Virological goal:*** to reduce the HIV viral load as much as possible – preferably to undetectable levels – for as long as possible.
2. ***Immunological goal:*** to restore and/or preserve immunological function so as to improve immune functioning, reduce opportunistic infections and delay the onset of AIDS.
3. ***Therapeutic goal:*** to improve the quality of the HIV-infected person's life.
4. ***Epidemiological goal:*** to reduce HIV-related sickness and death, and to reduce the impact of HIV transmission in the community.

From the above stated goals of ART, one can discern that ARVs are crucial in the lives of HIV positive people because they reduce the HIV viral load, improve one's immune system and quality of life, and reduce HIV-related morbidity and mortality. Flint (2011:88) states that the HIV sufferers totally rely on their access to ARVs for survival and the distribution of ARVs is now a vital aspect of HIV and AIDS management. Many countries are affected with the epidemic and their governments are making efforts to ensure that the ARV drugs are available to the public for free or at low costs.

There are different lines of ARV regimens such as the Nucleoside and Nucleotide Reverse Transcriptase Inhibitors (NRTIs/NtRTIs), a Protease Inhibitor (PIs) and a Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs) (van Dyk, 2012:11). Regimens are classified according to the antiretroviral agents in the group. There are various types of ARV medicines

and these are grouped according to their regimens. Van Dyk (2012:113) groups the ARV agents available in Southern Africa as follows:

**Table 1: ARV agents available in Southern Africa**

<b>Nucleoside/Nucleotide Reverse Transcriptase Inhibitors (NRTIs/NtRTIs)</b>	<b>Non-nucleoside Reverse Transcriptase Inhibitors (NNRTIs)</b>	<b>Protease Inhibitors (PIs)</b>
Zidovudine (AZT, ZDV) (Retrovir®)	Nevirapine (NVP) (Viramune®)	Indinavir (IDV) (Crixivan®)
Didanosine (ddl) (Videx®)	Efavirenz (EFV) (Stocrin®)	Saquinavir (SQV) (hard gel formation) (Invirase®)
Lamivudine (3TC) (Epivir®)		Nelfinavir (NFV) (Viracept®)
Stavudine (d4T) (Zerit®)		Ritonavir (RTV) (Norvir®)
Abacavir (ABC) (Ziagen®)		Atazanavir (ATV) (Reyataz®)
Tenofovir (TDF) (Viread®)		Fosamprenavir (F-APV) (Lexiva®)
Emtricitabine (FTC) (Emtriva®)		Lopinavir/ritonavir (Kaletra®)

Note: The names of the ARVs are presented in the following order—generic name (abbreviation) and trade name.

The patient starts ART after being assessed and it is seen that she is in World Health Organisation (WHO) clinical stage 3 or 4. Patients are initiated on ART by a doctor following several counselling sessions and the nurse provides support through meeting with patients at the local clinic on a regular basis (Campbell et al., 2011:176). Heywood (2004:251) further states that “patients need to be prepared for treatment readiness including education about their illness and drug literacy, and be given the tools to ensure that there is adherence to medicines.” Many HIV patients are defaulting treatment due to a number of factors such as lack of education regarding their condition and how to use the drugs, stigma and lack of support from their families and the community at large.

In 2003, WHO, the Joint UN Program on AIDS (UNAIDS) and the US President Emergency Plan for AIDS Relief (PEPFAR) launched the “3 by 5” initiative which aimed to cover ARVs for 3 million HIV patients by 2005 in poor countries (Bartlett & Shao, 2009:637; Suitcliffe et al., 2008:477). Substantial improvement has been made in the Sub-Saharan region through this initiative. It led to the scaled-up programmes in many countries and ARVs were accessed for free at an increased number of sites (Bartlett & Shao, 2009:637). It has been reported that about 1 million more people were receiving ART by the end of 2007 as compared to 2006 and the “3 by 5” initiative’s original plan has been met even though it was late (Bartlett & Shao, 2009:637). The initiative was successful to a greater extent, although the number of people needing ARVs is increasing every year.

Zimbabwe launched the national ART roll-out plan in 2004 (Zimbabwe National HIV..., 2006:9). HIV prevalence is on a decline in Zimbabwe; in 2001 the prevalence in the adult population was estimated to be 23,7% and declined to 18,4% and 13,11% in 2005 and 2011 respectively (Zimbabwean Ministry of Health and Child Welfare, 2012:9). In 2011, the Zimbabwean Ministry of Health and Child Welfare (2011:6) reported that 320 000 is the estimated number of people receiving ART and the majority of patients on ART were females; they contributed 60% of all patients in the public health sector. This fact is supported by UNAIDS (2008:130), which state that “[g]lobally, coverage of antiretroviral treatment for women is higher than or equal to that of men”. Many Zimbabwean women are receiving ARVs as compared to their male counterparts.

Fraser et al. (2010:28) propounded that “[l]ife-prolonging antiretroviral treatment (ART) helps to maintain the number of positive people at a high level in Zimbabwe despite about 84 000 AIDS deaths annually (2009 est.) and decreased number of new HIV infections.” This implies that the results of ART in the country are profound and are noticeable. ART coverage has increased from 55% in 2009 to 79,7% in 2011. The total number of ART sites in Zimbabwe was 590 by the end of 2011; 436 181 adults and 40 140 children were receiving ARVs (Zimbabwean Ministry of Health and Child Welfare, 2012:9, 31). Despite the enormous progress made in scaling up ART through the reduction in drug prices and use of generic drugs in the Sub-Saharan region including Zimbabwe, many challenges in accessing the drugs remain (Harries et al., 2010:60). Zimbabwe ART users face multiple obstacles in accessing ARVs. Women are at the centre of the world’s concern as far as HIV and AIDS are concerned; the epidemic wave has affected millions of women (Pratt, 2003:194).

South Africa has recently launched the Fixed Dose Combination (ARV) on 8 April 2013. This is a multiple antiretroviral drug combined into one and it contains emtricitabine, efavirenz and tenofovir (Khumalo, 2013:1; Makgalemele, 2013:15). The pill was introduced in a bid to reduce costs and also to improve adherence. It will be given to pregnant women, breast-feeding mothers and newly diagnosed HIV positive persons (Khumalo, 2013:1). This study is going to focus on women since they account for a greater percentage of people who need ART and they are considered a vulnerable group in society.

## **2.6 CHALLENGES FACING HIV POSITIVE WOMEN IN ACCESSING TREATMENT.**

### **2.6.1 Stigma and Discrimination**

Stigma is our worst enemy and it has worsened the problems of HIV positive women (Sandasi & Cherewo, 2006:3). Stigma and discrimination are the reasons many people do not disclose their HIV status to their friends and relatives. Stigma and discrimination come in varying forms such as self-stigma, stigmatization by the community and family stigma (Mahoro, 2005:23). Johnston (2001), as cited in Rohleder, Swatz, Kalichman and Simbayi (2009:18), states that “...there is a strong culture of silence by people living with HIV/AIDS because of fear of rejection and isolation from both close relatives and the community at large.” People hide their HIV status for fear of being ridiculed or suffering personal harm (Messer, 2004:68). Heywood (2004:220) further states that stigma has a major impact on an individual’s right to dignity, equality and access to health care services. Many people avoid visiting the ART clinics for fear of being seen visiting the facility. The success of treatment is substantially affected by fear of disclosure of one’s status to the family members and others (Bartlett & Shao, 2009:637). O’Leary and Jemmott (2010:72) support this notion by stating that emotional distress and isolation is reduced by having adequate social support from relatives and other women and it also fosters a context for improved self-care. This is not the case with many HIV positive women; they suffer in silence, finding it difficult to disclose their status to their families.

Messer (2004:68) asserts that stigma and discrimination are not only horrendous personal evils inflicted on the individuals, but they are social evils that undermine and threaten efforts of prevention, care, support and treatment by the Public Health Department. Non-adherence to treatment is as a result of stigma and discrimination in many communities. Hall (2007:57) states that “the epidemic primarily affects the world’s poorest communities with greatest gender

inequalities, disparities in income and access to productive resources, the marginalized, stigmatized and disempowered.” Women have been subjected to stigma, discrimination, violence and emotional torture when they are identified as being HIV positive.

The fear of taking ARVs openly affects adherence to the treatment regimen and this can lead to a different drug regimen. Second-line regimen is not easily available thereby limiting treatment options for the patients (Heywood, 2004:220). White and Carr (2005), as quoted by UNAIDS (2008:77), reiterate that “[f]ear of stigma and discrimination also makes people living with HIV less likely to seek care and treatment, adhere to treatment, and disclose their HIV status to their sexual partners.” HIV positive women fear physical and emotional violence as well as rejection if they disclose their status to their husbands or partners. According to Sandasi and Cherewo (2006:3) “[t]hey [women] have been ostracized and rejected, and this has led them to hide or neglect their condition. HIV-positive women have been reduced to low levels of self-esteem and feelings of uselessness. Many women have been physically abused for disclosing their status to their spouse.” Victimization and discrimination happens everywhere, starting in the patients’ homes, within their communities and at work (Rohleder et al., 2009:18). Stigma is a major challenge experienced by HIV positive women with regard to access and adherence to treatment.

Stigma would also be seen as a barrier to accessing HIV and AIDS treatment as people fear being identified as HIV positive when they are seen visiting dedicated programme areas of the clinics and hospitals to seek treatment (Karim & Karim, 2010:514; Training Manual..., 2005:22). From the studies conducted by Bartlett and Shao (2009:637), it has been found that in many countries vulnerable populations find it difficult to access ART and a substantial bias exists against women, which might prevent proper screening and treatment. HIV and AIDS are widely perceived to be as a result of sexual promiscuity and low moral standards, hence the reason why many HIV positive women do not want to disclose their status to their families. There is a great fear of disclosure after testing positive, as women are often blamed by their partners (Phiri, Haddad & Masenya, 2005:152). In some cultures when a woman is diagnosed with HIV and AIDS, stigmatization and bias are amplified and she might be disowned and abandoned (Messer, 2004:76; Common Wealth Secretariat, 2002:33). Sandasi and Cherewo (2006:3) support this viewpoint by stating that “[m]arried women have sometimes been abandoned by their husbands with no legal or economic recourse.” Women are treated as objects rather than individuals in many African societies.

Women also suffer stigma and discrimination at the hands of healthcare workers. Some healthcare workers are insensitive and judgmental towards HIV positive patients (Heywood, 2004:220; Training Manual..., 2005:22). Mahoro (2005:25) highlights that “[t]here is an assumption by health personnel that women with HIV must have contracted it through commercial sex work. As a result, positive women are subjected to dehumanizing treatment and negative attitudes.” Women who are used to neglect from healthcare workers may assume inadequate care and they end up not adhering to treatment regimen (O’Leary & Jemmott, 2010:72). Some healthcare workers are unwelcome and cheeky towards the HIV positive patients and this leads to patients not coming back for treatment. People infected by HIV face the dilemma of illness and discrimination, thereby losing their jobs, friends, family and even medical care when discovered that they are HIV positive (Messer, 2004:60). Despite the HIV and AIDS education and awareness campaigns, stigma and discrimination prevail and it is a major challenge to access ARV treatment.

### **2.6.2 Gender Inequality and Cultural Norms**

Many women find it difficult to access treatment due to their position in society. Rohleder et al. (2009:239) state that “[t]he inferior status of women in society perpetuates rampant infection among women, not only among single women but also married women who lose all capacity to negotiate safer sex.” In many African societies, women are considered a second-class citizen and their ability to influence decisions about sexuality and accessing healthcare is very limited (Karim & Karim, 2010:515). Men initiate, dominate and are in control of sexual interactions and reproductive decision-making (Commonwealth Secretariat, 2002:26; Mahoro, 2005:6; Sandasi & Cherewo, 2006:1). Most women are submissive towards their husbands and if their husbands refuse to let them get treatment, they have to follow their orders. Mahoro (2005:6) propagates that “[i]f the man says no, that means they [women] are grounded so access to health depends on the man’s willingness.” This is a big challenge experienced by married women and women in stable relationships. It is also difficult for women to convince their husbands to go for treatment and also to negotiate safe sex, especially the use of condoms in marriage.

The researcher supports this notion that young women are the ones at risk of the epidemic and this can be attributed to gender violence and cultural practices such as widow inheritance, widow cleansing and intergenerational sex (Flint, 2011:12). Most of the men who some women are married or attached to are older than them, thereby making it difficult to negotiate the use of condoms in a marriage or relationship. Women in many cultures are discriminated against

because of their gender and often they have little or no control over their sexual lives (Messer, 2004:68). Sandasi and Cherewo (2006:1) go further by stating that “...male pleasure is given priority over female pleasure and men have greater control than women over when and how sex takes place.” Women from poor backgrounds are forced to sell sex in exchange of money, food and other goods and in these sexual exchanges, women find it difficult to negotiate the use of condoms (Heywood, 2004:74). Negotiation for safer sex is a real challenge to many HIV positive women which leads to re-infection with other strains of HIV and resistance to ARVs.

Women often feel unable to insist on condom use during intercourse because it evokes anger and suspicion (Phiri et al., 2005:152). Men perceive themselves to be naturally superior to women and they often use physical violence to control and secure submission from women (UNAIDS, 2008:67). They also consider it their cultural right to have multiple sexual partners (Rohleder et al., 2009:17). According to Sandasi and Cherewo (2006:1), “...in Zimbabwe, as is the case throughout Southern Africa, it is culturally acceptable that men can have multiple sexual partners and women don’t.” It is in these relationships that women are re-infected with other strains of HIV. Women often attend treatment programs without disclosing their status to their untested and untreated partners and at the same time continue practicing unprotected sex with them (Karim & Karim, 2010:515). Gender inequality plays a major role in impeding HIV positive women’s access to treatment because they find it difficult to disclose their status, negotiate for safer sex and take their medication openly and consistently.

### **2.6.3 Location and Environmental Factors**

The distance between the ART clinics and where HIV positive women reside also affects access to treatment. The physical distance patients have to travel to collect their medicines limits treatment access for HIV positive women, particularly in rural areas (UNAIDS, 2008:152; Heywood, 2004:266). Healthcare facilities might be far away with HIV positive women having to travel long distances with inadequate transport or funding for transport (Training Manual..., 2005:21). Poor people may also have difficulty in obtaining money for transport to their ARV collection sites and struggle to access their medication regularly (Rohleder et al., 2009:98). Many HIV positive women are financially dependent on their husbands or partners and this makes it difficult for them to ask for transport money to travel to the ART sites, especially if they have not disclosed their status.

Distance and high costs associated with transport might make it difficult for patients to access ART clinics (Harries et al., 2010:62). This is even worse for bedridden patients who need special transport to go to ART clinics; failure by their families to pay their debts for previous transport and a lack of money for new transport means that the patient will not be able to access the treatment regularly (Rohleder et al., 2009:98). The distance between HIV patients and the ART clinic sites creates a creeping patient inertia leading to non-adherence of ARV treatment. The patient's access and adherence to treatment are affected by transportation to treatment centres, as well as having to take time off work to go for checkups and laboratory testing (Bartlett & Shao, 2009:637).

The ART clinic sites might also be too close; some women avoid going there for treatment for fear of disclosure and stigmatization. Others will resort to visiting ART clinics which are outside their areas because they are not known there. The problem of transport costs poses a major challenge to accessing ARV treatment. The transport for repeat visits is too high for many patients.

#### **2.6.4 Poverty and Economic Factors**

Poverty is another obstacle to accessing ARV treatment for HIV positive women in Zimbabwe. Poverty, lack of education and lack of economic opportunities, especially in the developing countries, increase the vulnerability of women to HIV infection. Rohleder et al. (2009:89) reiterate that “[t]he worsening economic situation is likely to continue to impact negatively on health and development, especially in countries that are already severely affected by HIV and AIDS.” Campbell et al. (2011:180) carried out a study in three rural hospitals in Zimbabwe on the nurses' and patients' perceptions of good clinical care for HIV-positive people on ARV treatment. Their findings report that most people are battling to pay one or two US dollars for the consultation fee (now the currency in Zimbabwe) each time they visit the ART clinic. They will also have to wait for many hours in long queues in order to pay the consultation fee, be weighed, have their temperature taken, see the nurse and collect medication from the pharmacy. This alone hinders HIV positive women from visiting the ART facility monthly to collect their medication.

On top of the one US dollar consultation fees, the patients have to purchase drugs for opportunistic infections, since the hospitals do not receive these medicines for free from the government. Only the ARVs and cotrimoxazole (a pre-ARV) are given for free (Campbell et

al., 2011:181). Mahoro (2005:23) supports this notion by stating that “[a]lthough treatment programmes have been initiated in most countries, often the focus is on ART and individuals have to pay for treatment for opportunistic infections.” Many HIV positive women, especially in rural areas, are living in dire poverty; they struggle to find one US dollar for survival, let alone for transport. They end up having to walk long distances to the ART facilities and they fail to do it on a monthly basis, thereby leading to defaultment. Most of the HIV positive women are financially dependent on their husbands; they have to ask their partners for money for transport, placing their access to treatment at the disposal of their spouses (Mahoro, 2005:19).

The researcher supports Heywood (2004:274) who states that patients are facing unnecessary handicaps in accessing treatment. Those who are working are forced to take a day off from work and sit in long queues for medication. Also unemployed women have to walk for long hours to collect their medicines, leaving behind their families to look after or attend to their fields. People have to wake up very early in the morning and wait for hours in very long queues before they are served (Campbell et al., 2011:181). This is not sustainable for many HIV positive women and hence they fail to come for review dates, dreading to endure long hours waiting in the queues before they receive treatment. Sometimes patients are denied drugs if they fail to pay the consultation fee or other times the fee is waived or is turned into a debt (Campbell et al., 2011:181). Waiting times is an important factor for patient dissatisfaction while accessing care and treatment service.

Rohleder et al. (2009:35) highlight that the challenges of HIV and AIDS “are massively exacerbated in contexts of poverty and underdevelopment, and made worse by periods of conflict and political intransigence.” This is especially true for Zimbabwe which has the largest number of people living with the epidemic in the Sub-Saharan region. This is also compounded by prolonged periods of drought and people are struggling to make ends meet. HIV positive women are not excluded from the bracket and they experience many challenges in accessing ARV treatment.

### **2.6.5 Nutritional Factors**

HIV positive women need a highly nutritious diet in order to boost their immune system. Mahoro (2005:6) highlights that “[o]ne cannot talk about effective treatment without adequate nutrition, as treatment without proper nutrition can be counterproductive.” Food security is the

greatest threat to the scale-up of antiretroviral treatment provision in some African countries heavily affected by HIV and AIDS (Rohleder et al, 2009:98). Karim and Karim (2010:490) go further stating that “[t]he HIV epidemic is now a leading cause of death in Sub-Saharan Africa and at a household level poses a major threat to food security as a result of diminished production, as well as the inability to purchase food.” Zimbabwe has gone through prolonged periods of drought coupled with the unfavourable economic and political climate in the country. Many HIV positive women struggle to put food on the table.

The country has experienced severe droughts in recent years leading to severe food and livestock shortages (Rupiya, 2006:160). ARVs are powerful drugs and patients cannot take them without a proper and dependable diet (Messer, 2004:144; Rupiya, 2006:160). It is critically important for HIV positive people to receive proper nourishment because of their declining immune system (Heywood, 2004:36). Asymptomatic micronutrient deficiencies may occur among HIV positive people in low income countries and they are common forms of poor nutrition (Karim & Karim, 2010:489; UNAIDS, 2008:149). This can be corrected with an adequate diet.

Karim and Karim (2010:489) further state that “there is evidence that improved diet can improve energy and nutrient intake in the people living with HIV/AIDS.” The HIV positive patients have to eat a well-balanced diet which is high in protein and calorifically dense food in order to maintain their body weight (Pratt, 2003:324). Human hunger and lack of food security are challenges for people who initiate ART and they have been shown to inhibit the uptake of treatment (UNAIDS, 2008:149; Messer, 2004:144). “Malnutrition has caused people living with HIV to develop AIDS faster, and is likely to have decreased the effectiveness of ARVs for those who are receiving treatment” (HIV and AIDS..., [sa]:8). Most women find it difficult to adhere to treatment due to lack of material needs, such as food and money.

The government of Zimbabwe wanted food to be channelled through them and the civil society and other donors were concerned that food could be used as a campaigning tool during the national and local government elections (Rupiya, 2006:160). Many international food donors pulled out of the country and the HIV positive women continue to suffer from hunger and starvation. According to HIV and AIDS...([sa]:10), “[t]he government has been increasingly hostile towards foreign non-governmental organizations (NGOs), to the extent where they threatened to pass a law that would give the government the power to interfere with how NGOs

are run.” As a result of this hostility many countries have withdrawn their food and medical aid to the country. Rupiya (2006:159) states that “malnutrition has a direct impact on the human body’s response to HIV/AIDS.” ARVs cannot be taken on an empty stomach and a lack of adequate food compels many HIV positive women not to adhere to their treatment.

### **2.6.6 Shortage of Healthcare Workers**

There are not enough healthcare workers to serve HIV positive people visiting the ART clinic sites. The critical shortage of human resources due to freezing of posts, poor working conditions, poor remunerations and the migration of healthcare workers to the private sector and abroad has been seen as the greatest weakness in the health infrastructure of Southern African countries (Heywood, 2004:218; Zimbabwean Ministry of Health and Child Welfare, 2012:41). Shortage of staff due to staff turnover is a major challenge facing the smooth access of ARV treatment in Zimbabwe. In many low-income countries, there are few highly trained healthcare personnel at all levels and the provision of care is seriously affected by costs of training and remuneration (Bartlett & Shao, 2009:638; Suitcliffe et al., 2008:477). The number of HIV positive people on ART is increasing every year thereby overwhelming the few healthcare workers available.

Campbell et al. (2011:181) conducted a research on three rural hospitals in Zimbabwe and they discovered that the hospitals have two days of ART each week, namely on Mondays and Wednesdays. This arrangement was made in order for the healthcare workers to focus only on ARV patients on that day rather than to flip back and forth through the register of the patient. This arrangement poses a challenge to HIV positive women because if they miss those specific ART days it means they will not get their treatment on time. This also leads to long and gruesome waiting queues at ART clinic sites. Countries such as Zimbabwe, Tanzania, Malawi and Mozambique would need to boost their current stock of qualified health workers in order to reach the 2015 target of universal access to ART (van Damme et al., 2008:2110). The healthcare workers are suffering from burn out; they are overloaded with work and as a result they stigmatize people with HIV.

Many factors contribute to the overall shortage of healthcare personnel, such as the increasing external brain drain and weakness of the national medical education and training programmes (UNAIDS, 2008:154; van Damme et al., 2008:2110). Many healthcare workers are leaving the country for neighbouring countries and overseas, looking for greener pastures. Studies have

shown that in Sub-Saharan Africa, being hit the hardest by the epidemic, there are few health workers who have to cope with ever increasing workloads resulting in emotional and physical distress and job dissatisfaction (Van Damme et al., 2008:2111). According to UNAIDS (2008:153), “[a]cute shortage of healthcare professionals impede treatment scale-up in many of the countries heavily affected by the epidemic.” Some healthcare workers are also HIV positive and this affects staff availability and morale. Staff shortage and absenteeism increase, thereby weakening the already overburdened health system (Heywood, 2004:219). The shortage of healthcare workers has a negative impact on HIV positive women’s access to ARV treatment.

### **2.6.7 Logistics and Technological Issues**

The prevailing economic condition in Zimbabwe makes it difficult to procure enough ARV drugs for all HIV positive patients. Heywood (2004:215) states that “[i]n Zimbabwe, the economic and political turmoil has affected healthcare services and reduced donor support.” Many donors have pulled out and this has affected the access of ARV treatment for HIV positive women. High staff attrition, limited financial resources, inadequate and constant breakdown of CD4, and biochemistry and haematology machines are some of the challenges of ART programmes (Zimbabwean Ministry of Health and Child Welfare, 2012:32). HIV positive patients have to visit the hospital laboratories for regular testing of the viral load. The prolonged waiting times between tests and results slow the pace of treatment delivery (Heywood, 2004:219).

The system of referral for expert assessment to major district or provincial hospitals for second line drugs and the back referral to the ART clinics are quite demanding for the healthcare workers and the second line drugs are expensive for patients (Harries et al., 2010:62). An insufficient amount of laboratories, poor-quality equipment, a lack of access to laboratory testing and the substantial costs of these tests delay treatment and lead to higher morbidity and mortality rates (Bartlett & Shao, 2009:638). The study carried out by Campbell et al. (2011:18) in three rural hospitals in Zimbabwe reported that when ARVs were in short supply, the patients were given fewer pills and were ordered to come back for refills and this sapped the already limited economic and physical resources of patients. Mahoro (2005:19) supports this idea by mentioning that “[t]he issue of sustainability is also a matter of concern because sometimes patients are told that part of the regimen has not arrived so you are given drugs for few days and told to come back for the rest of the supply some days later.” It has been noticed that stock-

outs are a common problem for many health facilities in resource limited countries (UNAIDS, 2008:55). The unavailability of ARV drugs is a major challenge experienced by HIV positive women in Zimbabwe.

Poorly developed drug procurement and distribution systems, and unaffordable assays for monitoring response to therapy and medication effects have been seen as the major obstacles to ART (Suitcliffe et al., 2008:477). Bartlett and Shao (2009:638) support this notion by stating that inconsistent drug supplies and breaks in the supply chain due to the logistics and costs of distribution to various ART sites, especially in rural areas, are the major challenges to ART programmes. Regarding the technological issues, Heywood (2004:19) mentions that “[l]aboratory and pharmacy facilities, trained laboratory technicians and pharmacists, and the acquisition and maintenance of equipment are inadequate, particularly in rural areas.” Health service infrastructure, doctors and nurses are minimal if not nonexistent in rural areas.

The shortage of foreign currency to purchase commodities including ARVs, OI treatment (such as TB drugs and cotrimoxazole) and laboratory reagents, a weakened infrastructure and the high prices of ARVs in the private sector have been seen as some of the factors that hamper the availability of AIDS treatment (Zimbabwe National HIV..., 2006:10). HIV positive women have to travel to district or provincial hospitals for laboratory tests and there they might find very long queues or that the machines are not working. This poses a challenge to ARV treatment access, and because of the frustrations they encounter at the hospitals and ART clinics some end up defaulting treatment.

### **2.6.8 Witchcraft and Personal Beliefs**

The way HIV positive women believe in witchcraft or their religion has an impact on their access to ARV treatment. WHO (2008b), in Flint (2011:62), has reported that up to 80% of the people living in Sub-Saharan Africa make regular use of the traditional healers’ services. According to Harries et al. (2010:62), “[i]n many rural settings, patients might also choose not to present to medical clinics, frustrated by unavailability of external medicines and coupled with a strong belief in traditional medicine.” The long distances travelled, the gruesome hours they wait before being attended to and the insufficient ARV supply led to some HIV positive women resorting to traditional medicines.

Many Africans who are poor and uneducated associate the HIV and AIDS pathogenesis with witchcraft and sorcery (Karim & Karim, 2010:512; Rohleder et al., 2009:14). As a result many seek care from traditional healers and consume traditional remedies. Some of the people infected with HIV believe that traditional remedies are part of a range of options available to them, instead of using ARVs (Flint, 2011:15). Some women with HIV and AIDS consult with the traditional healers and faith healers and are forced or convinced to stop taking their treatment. This leads to defaultment and instead they will use herbs and unclean water which will interfere with their health. This belief system has an impact on the access to ARV treatment.

Two herbs common to traditional remedies across Africa, sutherlandia (Cancer Bush) and hypoxis (African Potato), appear to interfere with the efficacy and metabolism of some ARVs (Flint, 2011:101). Some patients might think that drugs would not make a difference to them or that the unpleasant side effects outweigh the benefits (Training Manual..., 2005:22). Some patients believe that when one is HIV positive, she has to look thin and sickly. Most patients rarely visit the clinics for ARV refills and checkups when they are in good health (Campbell et al., 2011:179). Drug availability or price does not guarantee effective treatment; it is also necessary for people to have faith in the treatment on offer (Flint, 2011:88). For the HIV positive women to adhere to ARV treatment, they have to change their beliefs on the association of HIV and AIDS with witchcraft.

## **2.7 SUMMARY**

The researcher used the Health Behaviour Theory in order to understand the actions of HIV positive women. This will help her to understand why some women do not adhere to ARV treatment. The biopsychosocial model was utilized because it is a holistic approach to care and treatment. It looks at the individual as a whole socially, psychologically and physically. Factors such as the individual's belief system, culture, and socio-economic status was looked at with regard to their impact on ARV treatment.

HIV and AIDS are ravaging every aspect of people's lives. Sub-Saharan Africa accounts for the highest prevalence of the epidemic and the largest number of people with the disease are women. This can be contributed to their position in society and the cultural norms which oppress them. Greater efforts were made to scale-up the provision of ARV treatment to HIV

positive patients. Due to the prevailing economic and political turmoil in Zimbabwe there are many challenges experienced by HIV positive women in accessing ARV treatment, such as the shortage of healthcare workers, stigma and discrimination, and nutritional factors, just to mention a few.

In Zimbabwe more research on the challenges facing HIV positive women in accessing treatment needs to be done. This information will be useful because it may assist in improving the provision of services in the future, with recommendations that may assist in the provision of HIV treatment to the marginalized groups in society.

In the next chapter, the researcher will be discussing the research findings.

## CHAPTER 3:

# RESEARCH METHODOLOGY AND EMPIRICAL RESEARCH FINDINGS

### 3.1 INTRODUCTION

This Chapter looks at three aspects of the study: the research methodology, a profile of research participants, and the research findings emerging from the interviews on the challenges experienced by HIV positive women with regard to ARV treatment in Zimbabwe. The information obtained from the interviews with the participants was transcribed and analyzed and the research findings will be presented by means of themes and sub-themes that were identified during data analysis and are supported with verbatim quotes from interviews and literature. At the end of the chapter, a summary of the research findings will be given.

The goal of the research was:

- ❖ **To explore the challenges experienced by HIV positive women with regard to accessing ARV treatment in Zimbabwe.**

Objectives were formulated in order to attain the above goal. The objectives of the research were as follows:

- ❖ To describe the phenomenon of HIV and AIDS in Southern Africa and specifically in Zimbabwe, the position of HIV positive women as a vulnerable group in society, and ARV treatment.
- ❖ To explore the challenges experienced by women with HIV and AIDS in Zimbabwe.
- ❖ To explore the challenges of HIV positive women in accessing and adhering to ARV treatment in Zimbabwe.
- ❖ To make recommendations for improving services in Zimbabwe.

The following research question guided this study:

**What are the challenges experienced by HIV positive women with regard to antiretroviral treatment in Zimbabwe?**

## **3.2 RESEARCH METHODOLOGY**

### **3.2.1 Research Approach**

The study adopted a qualitative research approach in order to get responses from women with HIV and AIDS with regard to the challenges and experiences they faced in accessing and adhering to ARV treatment, which is a sensitive topic. Fouché and Delport (2011:65) reiterate that “[t]he qualitative research paradigm in its broadest sense refers to research that elicit participant accounts of meaning, experience and perceptions. It also produces descriptive data in the participant’s own written or spoken words.” The approach mainly focuses on meaning, language and cultural experiences in social contexts and is mainly concerned with understanding particular situations rather than generalizing findings (du Plooy, 2011:136). This approach was useful for the study, because it allowed the researcher the opportunity to gather data on a sensitive topic as it was revealed by the participants and also to have personal contact with the participants and also gathered rich in-depth data.

A qualitative research approach takes place in the natural setting. The emphasis is on the participants’ perspective and the multiple methods used in collecting data are interactive and humanistic in nature (Creswell, 2003:181; Babbie & Mouton, 2001:309). The researcher was concerned with understanding the reality of the phenomena; getting information from the HIV positive women themselves. The chosen approach provided the researcher with more insight and understanding of the challenges experienced by HIV positive women with regard to ARV treatment in Zimbabwe.

### **3.2.2 Type of Research**

Applied research was utilized for this study. The researcher wanted to know the problems the HIV positive women encountered in accessing and adhering to ARV treatment in Zimbabwe and devise possible recommendations. Applied research is normally used to assist the community in solving a particular problem they are facing and the basic research findings are applied to the challenges of the community (Bless & Higson-Smith, 2000:39). The researcher sought to gain an in-depth understanding of the ARV treatment challenges and experiences in Zimbabwe.

### **3.2.3 Research Design and Methodology**

#### **3.2.3.1 Research design**

The research design for this study was the case study design. This was because the researcher wanted to explore the challenges and experiences which HIV positive women encountered in accessing and adhering to ARV treatment. The case study design also gives an in-depth description of the case. Fouché and Schurink (2011:321) propounded that “...the case study serves the purpose of facilitating the researcher’s gaining of knowledge about the specific social issue.” In the context of this study, the social issue was the challenges and experiences of HIV positive women in accessing and adhering to ART.

The type of case study that was used in this study was the collective case study design. According to Fouché and Schurink (2011:322), “collective case study is an instrumental case study extended to a number of cases.” The researcher was more interested in the group’s opinion than the individual’s opinion, and thus she chose this type of research design. The case study design enabled the researcher to gain information on the experiences and challenges facing this group of women.

#### **3.2.3.2 Research population, sample and sampling method**

- **Population**

The research population for this study was the African women from Zimbabwe who were infected with HIV and AIDS. The population possesses specific characteristics that the researcher is interested in and from which the sample will be drawn (Strydom, 2011:223). The population for this study was therefore women living with HIV and AIDS in Zimbabwe, who were accessing ART.

- **Sample**

The sample for this study comprised of 10 women living with HIV and AIDS in the Masvingo District, Zimbabwe, who were accessing ART. A sample provides the researcher with more accurate information. Due to limited time and the resources, the researcher was not able to conduct the research study with the entire population. “A sample is a set of individuals selected from the population and usually is intended to represent the population in the research study” (Gravetter & Forzano, 2009:128). These were the specific individuals who took part in the research study and the sample was

studied in an effort to understand the population from which it was drawn. Although a small sample is less accurate, it is more convenient (Bless & Higson-Smith, 2000:93).

#### ▪ **Sampling method**

The non-probability sampling method was used in the study. This method of sampling was applicable to this study because the researcher did not know the population of HIV positive women in the district. Non-probability sampling is used in cases where the researcher does not know the population size and also does not use an unbiased method of selection (Gravetter & Forzano, 2009:133). The participants did not have the same chance to be selected, since their population size was unknown. The type of non-probability sampling that was relevant for this study was the purposive or judgmental sampling. Kumar (2005:179) postulates that “the primary consideration in purposive sampling is the judgment of the researcher as to who can provide the best information to achieve the objectives of the study.” The researcher purposively selected participants using certain criteria to ensure that the sample contains an appropriate group of women. The researcher identified two NGOs in the Masvingo district of Zimbabwe from which she obtained verbal permission, and also their official letters of permission to conduct the study with their clients. The criteria for the sample were as follows:

- Black, Shona-speaking women
- Above 18 years old
- Living in Masvingo district of Zimbabwe
- Diagnosed as HIV positive and on ARV treatment for 1 year or more
- Receiving ART
- Marital status was irrelevant
- Literate
- Clients of either one of two NGOs: Batanai HIV and AIDS Service Organisation or the Reformed Church in Zimbabwe Community Based AIDS Program

The researcher went to the support groups and outreach programmes of the two above-mentioned NGOs with letters and read them explaining the purpose of the research. The researcher left copies for those people who were interested in partaking in the study voluntarily so that they could provide their contact details. The researcher then collected the contact details and contacted them. It was difficult to stratify the participants according to their age groups because the numbers were not proportional. Some of the HIV positive women were not willing

to take part in the research without getting payment for their involvement, hence the first 10 who met the criteria were sampled. The researcher purposively selected 10 HIV positive women – five from the rural areas and five from the urban area – in order to hear the experiences from both areas. Appointments were made with each participant to firstly discuss the letter of informed consent. Thereafter the interview was arranged and conducted at a convenient time and venue for the participant. Participants were comfortable to be interviewed in their homes.

### **3.2.3.3 *Data collection method***

Data for this study was collected through interviewing the participants individually and face-to-face. This enabled the researcher to obtain more information regarding the challenges experienced by HIV positive women with regard to ARV treatment, based on the verbal and non-verbal cues that were observed during the interviews. Babbie and Mouton (2001:259) highlighted that “a qualitative interview is essentially a conversation in which the interviewer establishes a general direction for the conversation and pursues specific topics raised by the respondent.” The interviews allowed the researcher the opportunity to interact with the participants and helped to uncover information of the participants’ perceptions, feelings, opinions and thoughts.

The interview allows the participants to express their feelings and thoughts, that is, the focus is on the individual’s experiences and perspectives (Neuman, 2003:391). The researcher used the semi-structured interviews. In a semi-structured interview, the researcher uses an interview guide with a list of all questions and areas that need to be covered during the session (Bernard, 2000:91). This type of interview enabled the researcher to gain information that was detailed in nature and questions were formulated on an interview schedule to guide the interview. According to Greeff (2011:352), the interview schedule guides the researcher and it compels the researcher to think openly and critically about the areas to be covered by the interview. This implies that there was more flexibility and certain themes and sub-themes were used to guide the researcher throughout the interviewing process. Each interview process took between 40 minutes to one hour depending on the issues raised by the participants. The interview was conducted at a convenient time and venue for each participant. They were comfortable to be interviewed in their own houses. Privacy was ensured by conducting the interviews in a private room.

Taking down notes as the interview progresses is very distracting for the researcher and the interviewee and the researcher may also miss crucial relational aspects of the interview (Darlington & Scott, 2002:59). The researcher used a digital recorder to collect information from the participants with their permission. Neuman (2003:386) highlighted that tape recorders “help a researcher recall events and observe what does not happen, or non-response, which are easy to miss.” The use of a digital recorder enabled the researcher to observe and monitor the feelings and emotional reactions of the participants to the topic being discussed during the interview.

#### **3.2.3.4 *Methods of Data Analysis***

Coding procedures were used in the analysis of data whereby the researcher took the voluminous amount of information and reduced it according to certain patterns, criteria and categories or themes. Schurink, Fouché and De Vos (2011:410) highlight that “...this step in the analytic process demands a heightened awareness of the data, a focused attention to it, and an openness to the subtle, tacit undercurrents of social life.” The researcher interviewed the participants in their own language, namely Shona, and converted the information into English during the transcriptions. The data gathered was transcribed verbatim into text and then analyzed. Data analysis is viewed by Henning (2004:10) as “...a process that requires analytical craftsmanship and the ability to capture understanding of the data in writing”. Once transcribed, the researcher grouped the information provided by the participants into categories, themes and sub-themes.

The steps that were followed by the researcher in analyzing the collected data were those mentioned by Marshal and Rossman (1999), as quoted by De Vos, Strydom, Fouché and Delport (2001:403). These steps were used to guide the researcher in the process of qualitative data analysis and were not fixed. The steps were as follows:

- **Preparing and organising the data:**
  - **Planning for recording of data.**

The researcher made sure that the tape recorder was available with spare charged batteries. All the interviews were digitally recorded and transcribed thereafter. Appointments were made with the participants and the interview venue was arranged before the interview commenced. The interviews took place at the participants’ houses. The researcher gave comprehensive information to the

participants regarding the purpose of the study and sought their consent. The participants were referred to as Participant A, B and C so as to ensure their right to confidentiality.

- **Data collection and preliminary analyses**

This step entails that whilst the researcher was busy interviewing the participants, data analysis also started and this enabled the researcher to come up with the richest possible information. Interviewing techniques such as probing, reflecting and paraphrasing, just to mention a few, were utilized in order to get more in-depth information. The researcher was also able to observe the participants' home circumstances and their body language, and she adapted her ideas to ensure that in-depth data was gathered.

- **Managing the data**

During the interviews, the researcher made field notes based on the observations made. A folder was created for each participant where her interview information was kept and the researcher transcribed each and every interview herself. The researcher also organized and managed all the field notes and transcripts. An audiotape and back-up copies were also made. Confidentiality was of paramount importance to the researcher, hence the participants were referred to as Participant A, B and C instead of using their real names.

- **Reading and writing memos**

During this step, the researcher went through the transcriptions several times in order to become familiar with the data and come up with a holistic picture of what has been revealed by the data.

- **Reducing the data:**

- **Generating categories and coding the data**

The researcher repeatedly read the transcripts, so that she was able to notice the statements mentioned by the participants and this assisted in structuring the whole amount of data into themes and sub-themes. The researcher used a highlighter to code every theme and sub-theme. In this instance, the researcher

also gave a name to the theme identified, described it and made quotations from the transcripts and contextualized it with literature.

- **Testing the emergent understandings and searching for alternative explanations**

In this case, the researcher made sure that she understood the meaning of the theme in the context of the interview. The researcher went to the literature and searched for other ways of explaining the theme.

- **Interpreting and developing typologies**

The researcher tried to make sense of the data collected and developed systems for categorising things or concepts, making sure that they were exhaustive and mutually exclusive.

- **Visualising, representing and displaying data:**

- **Presenting the data**

The researcher wrote a report for the public reading based on the data gathered, themes, categories and patterns generated, as well as the alternative explanations researched.

### **3.2.4 Trustworthiness of Data**

To ensure trustworthiness of the study, the researcher applied the following assumptions of the qualitative paradigm which were proposed by Lincoln and Guba (1999), in De Vos et al. (2011:419):

- *Credibility*—which is the investigation of the study. This captures the traditional concept of validity. “An in-depth description showing the complexities of variables and interactions will be so imbedded with data derived from the setting that it cannot help but be valid.” To achieve this, the researcher made sure that she and the participants were both prepared for interviewing so as to get the richest data. The researcher made sure that the time and venue for the interviewing was acceptable to the participants and that they understood what the study would entail, in order to get rich information. The participants were also informed beforehand that they could withdraw from the study at any time and that they could choose not to respond to any of the questions which they did not feel comfortable discussing. No participant withdrew from the interview, or

refused to answer the questions asked. The researcher clarified some of the statements by probing, in order to be certain of the information provided.

- *Transferability*—this entails the applicability or the generalisability of the results to other contexts. The researcher used rich data from multiple cases and informants to strengthen the study’s usefulness for other settings in the field of HIV/AIDS and women. Data collected from the participants was used in such a way that it was transferable to other areas in the field of HIV and AIDS. Another researcher can use the information in this study to conduct the same study in a different area or setting.
- *Dependability*—this replaces reliability. The qualitative approach believes that the world is not consistent; it is always changing and the positivist concept of replication is itself problematic (Schurink, Fouché & De Vos, 2011:421). The researcher took note of the ever-changing political and economic situation in the country. The researcher remained open to possible changes in terms of availability and accessibility of ARV treatment in Zimbabwe. The environments were inconsistent: the researcher had to travel to the participants’ houses both in rural and urban areas to conduct the interviews. She respected the participants’ choices.
- *Conformability*—it replaces the traditional concept of objectivity. The researcher carried out a detailed literature review so that she could evaluate herself, but relied on the literature and data obtained from the participants. The researcher also ensured that the findings represent rich and accurate descriptions of the participants’ experiences as told by them.
- *Researcher bias*—being a Zimbabwean and doing research in her country, the researcher was wary of and tried to avoid researcher bias. She looked objectively at the situation and tried to avoid being emotionally attached to the case. Personal opinions were suspended in order to make findings unbiased. The researcher used the strategy of reflexivity. According to Johnson (1997:283), “[t]his involves self-awareness and ‘critical self-reflection’ by the researcher on his or her potential biases and predisposition as these may affect the research process and conclusions.” The researcher reflected on her own perceptions and views on the study in order to identify her own biases. Having observed some of the challenges of HIV positive women, she tried not to let that information overshadow the whole process. The researcher also knew some of the participants; some were relatives and some lived in the area. This made the interview difficult as some of the participants were now looking for help or advice on the problems they were facing. Being a woman and also having relatives who

are HIV positive, the researcher tried to distance herself from preconceived ideas and biases. She became self-aware and tried to monitor and control biases. Given the fact that the researcher is a social worker by profession, the urge to counsel or give advice to the participants about the problems they were facing arose, but she tried to suppress it and stayed focused as a researcher and not as a counsellor or a therapist. These issues were dealt with during the debriefing session with each participant and were referred to the relevant social workers at the Social Welfare office for the area.

The researcher further used the strategies indicated by Johnson (1997:283-289), namely:

- ✓ *Data Triangulation* – this entails “[t]he use of multiple data sources to help understand a phenomenon” (Johnson, 1997:289). The researcher collected data from both rural and urban areas at different times and from different households. This assisted the researcher in gaining a better understanding of the challenges experienced by HIV positive women with regard to access to ARV treatment.
- ✓ *Theory Triangulation* – the researcher made use of many different literature sources to interpret and explain the experiences of HIV positive women. The researcher also consulted experts in the field regarding the study. Theory helped to explain and interpret the experiences of HIV positive women with regard to access to HIV treatment.
- ✓ *Low inference descriptors* – the researcher used the participants’ direct quotations to interpret and analyze the data. This would help the readers to have a better understanding of the themes and sub-themes discussed. This also helped the researcher to have a clear insight of the HIV positive women’s experiences.

### 3.3 PILOT STUDY

Pilot testing entails testing a small study before the actual study has commenced. The researcher conducted a small study with two participants in order to assess the feasibility and data collection method of the study. This allowed the researcher to make modifications where necessary, such as the interview schedule, and also to focus on certain areas that have been ambiguous previously so as to ensure quality interviewing during the main investigation (Strydom & Delport, 2011:395). For the purpose of this study, the researcher conducted the pilot test with two women who met the sampling criteria and were clients of the two NGOs.

These participants were not included as part of the main study. The methods of data collection specifically were tested and adapted where it was needed.

The study was feasible for the researcher in terms of time factor. The researcher visited the NGOs during a visit to Zimbabwe in May 2012 to identify two suitable NGOs and to get permission to use their clients in the study. Verbal permission was obtained and formal permission on a letterhead was received. The researcher was also able to get more information with regard to the need for research on this topic in Zimbabwe. By doing so, the researcher found it was easy to get the participants for the study. According to Strydom and Delpont (2011:395), it is of paramount importance for the researcher “to undertake as comprehensive and accurate an assessment as possible of the real situation to be investigated.” It was important to ascertain the practicality and reality of the study before the actual research study started. The researcher covered all the costs, including travelling expenses. Study leave was taken during the period of the study in Zimbabwe and no accommodation costs were incurred since the researcher was staying with her family.

### **3.4 ETHICAL ASPECTS**

The researcher adhered to research ethics throughout the whole study. Gravetter and Forzano (2009:98) propounded that “research ethics concerns the responsibility of researchers to be honest and respectful to all individuals who are affected by their research studies or their reports of the studies.” This entails that ethical issues are used to protect the interests of the participants.

#### **3.4.1 Avoidance of Harm**

The researcher tried to avoid or minimize any kind of possible harm to the participants, especially emotional harm. The participants were informed beforehand about the emotional impact that the study could have, so that they knew what to expect from the research study. Neuman (2003:12) pinpointed that “social research can harm a research participant in several ways: physical harm, psychological harm, legal harm, and harm to a person’s career or income.” The participants could possibly suffer emotional harm during the research process. Gravetter and Forzano (2009:107) support this opinion by mentioning that in cases in which the participants feel that they have been cheated, tricked or deceived, feelings of anxiety, anger, lower self-esteem and mild depression are common during or after the study. The researcher also organized beforehand with the social workers working in the area and referred the

participants who needed help. No signs of trauma or harm were noticed during the research study. The researcher debriefed the participants after the interviews and gave them her contact details should there be any need for further referral to be made to the psychologist or social worker.

### **3.4.2 Informed Consent**

According to Gravetter and Forzano (2009:107), "...human participants should be given complete information about the research and their roles in it before agreement to participate." In this regard the information should be clear and understandable, so that the participants will make the decision to participate voluntarily without force or coercion. Neuman (2003:121) further highlighted that "it is not enough to get permission from people; they need to know what they are being asked to participate in so that they can make an informed decision." To achieve this ethical issue, the researcher gave participants written informed consent letters which informed them of the purpose of the study, interview content, use of a tape recorder and possible consequences which they might endure through their participation. The researcher also made sure that the participants who took part in the research were well versed in Shona and were literate. Each and every participant that took part in the study had the letter of informed consent explained to them in Shona. When the participants voluntarily agreed to participate, they signed the informed consent letter to show that they were taking part in the research study out of their own free will and that they have clearly understood the content of the letter and the purpose of the study.

### **3.4.3 Violation of Privacy/ Anonymity/ Confidentiality**

To maintain privacy and confidentiality, the researcher did not associate the participants' names with the information provided. Babbie (2007:65) states that "a research project guarantees confidentiality when the researcher can identify a given person's responses but promises not to do so publicly." The research data was processed in a code system and letters were used to refer to the participants as Participant A, B and C. This was done to protect the privacy of the participants and also to ensure confidentiality. As the researcher interviewed the participants personally, anonymity could not be achieved. The organization informed their clients of the study. Those who were interested to take part in the study wrote their names down on a list, which was given to the researcher. The researcher contacted the participants who met the sampling criteria and made an appointment. The researcher also respected the privacy of the participants by conducting the interviews in a place where nobody was able to observe or

hear what was being discussed. The participants were also informed that the data would be kept for 15 years at the Department of Social Work and Criminology, University of Pretoria.

#### **3.4.4 Deception of Subjects**

The researcher did not wish to deceive or bribe the participants in any manner. Corey et al. (1993), as cited in De Vos et al. (2011:119), propounded that “[d]eception involves withholding information, or offering incorrect information in order to ensure the participation of subjects when they would otherwise possibly have refused it.” To avoid deception of subjects; the researcher provided information to the participants regarding the nature and content of the research study.

#### **3.4.5 Debriefing of Respondents**

The researcher took the opportunity to debrief the participants at the end of the interview to minimize any harm. It is necessary to provide opportunities to debrief the participants after the research interview and refer them to appropriate services, and this should be arranged during the planning stages of the research (Darlington & Scott, 2002:28). The researcher made plans beforehand with the social workers working in the area to refer the participants for counselling if needed. Debriefing was necessary as a result of the intrusive nature of the qualitative interviews. According to Babbie (2007:67) debriefing are the interviews done to correct the problems generated by the research experience. It helps to assess how the individuals’ participation in the research has affected them and counsel them to correct the problem. The researcher debriefed the participants after the interview, in order to give the participants the opportunity to work through the experiences of the study. Some of the participants were referred to a social worker in their area for counselling.

#### **3.4.6 Releasing or Publishing the Findings**

The whole purpose of research is to release the findings to the public. The researcher came up with correct and true information in the research report and avoided misinterpretation of the data gathered during the study. Babbie (2007:69) cited that “...science progresses through honesty and openness; ego defenses and deception retard it.” For the purpose of the profession, the researcher was truthful in the research, stating all the pitfalls and problems encountered during the research study. The findings of the research study should be introduced to the reading public in a written form, otherwise the study will not be of any significance or value (Strydom, 2011:126). The researcher informed the participants beforehand that the findings of

the research study were going to be published in a written form for academic purposes, but that they would remain anonymous. The researcher will also inform the participants of the summary of the findings of the research study. The mini-dissertation will be made available in the University of Pretoria library and a copy will be provided to both the Batanai HIV and AIDS Service Organisation and the Reformed Church in Zimbabwe Community Based AIDS Program. A manuscript with the researcher's supervisor as a co-author will be submitted to an accredited journal for publication.

### 3.5 PRESENTATION OF THE RESEARCH FINDINGS

The research findings will be presented by first indicating the profile of the research participants followed by the presentation of the themes and sub-themes identified. Literature and verbatim quotes from the interviews will be used to substantiate the themes and sub-themes. Where "...” is shown, it means some of the information has been left out as it was not relevant to the particular theme or sub-theme being discussed. The participants were identified as A, B and C to guarantee their confidentiality. A true reflection of data obtained from the interviews was provided by the researcher as far as possible.

#### 3.5.1 Profile of Participants

Purposive or judgmental sampling was used for this study where by five participants from rural areas and five participants from urban areas were selected. After interviewing all 10 participants, data saturation was reached. There was clear repetition of themes and sub-themes throughout all the interviews, hence the researcher chose not to add more participants to the sample.

**Table 2: Profiles of research participants**

Participant A	Participant A lives in a rural area in a three room brick house and there is one rondavel house on the property. She is married and has three children who are of school going age. Her husband works in Harare and they see each other once every three or four months. The family survives on subsistence farming and they also have a small garden where they grow vegetables for the family's consumption. Participant A is not well-educated and is not working; she depends on her husband
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	<p>for financial support. She was diagnosed with the disease in 2006 and started taking ARVs the same time. Her husband is a discordant partner and he is not on treatment. Participant A travels about 24km to the ARV treatment site and she pays \$4 for a return trip. She is affiliated to Guta RaMwari Apostolic church.</p>
<p>Participant B</p>	<p>Participant B separated from her husband after he married two more wives after her. She lives in a rural area with her biological father who is unemployed. She is a mother of two children and her children are living with her husband's other wife. She is fighting for custody of her children. She stopped schooling in Form 4 and she is unemployed. She depends solely on her husband for financial support. She discovered her HIV status in 2009 when she developed herpes zoster on her left side and her CD4 cell count was 17mm<sup>3</sup>/cell. That is the same period she started taking ARV treatment. Her husband has tested HIV negative. He has undergone all the advanced tests, but the results still come back negative. Participant B goes to the Apostolic Faith Mission church. She collects her treatment about 4km from where she stays. She walks to the ARV treatment site due to financial difficulties.</p>
<p>Participant C</p>	<p>Participant C lives in an urban area with her husband who is also HIV positive and is on ART. The couple lives in the sitting room, which is divided with a curtain that other tenants pass through when going to their own rooms. There is no water or electricity at the premises; they use fire for cooking purposes. They fetch water from the borehole which is about 2km from their house. Participant C has three children and two of them are living with her mother in a rural area. She lives with the last born who is two years old. Participant C dropped out of school when she was in Grade 7 and she is not working due to ill-health. She depends on her husband for financial support. Her husband works for a warehouse as a shop assistant. Her first husband passed away in 2002 and she met her current husband in 2009. She was diagnosed with HIV about 2 years ago and that is when she started</p>

	<p>taking the ARVs. The family is spiritual; they attend the Apostolic church and they go there on Thursdays, Fridays and Sundays. Participant C collects her medication from the provincial hospital where she pays \$1 for a return trip.</p>
Participant D	<p>Participant D is a mother of three children, who are now all adults. She stays in a rural area at her parents' house with her two year old granddaughter. She is a widow (her husband passed away in 2003) and she was in a polygamous marriage. She stopped schooling in Form 2, hence the chance of getting a formal job is very limited for her. She survives on subsistence farming and she also sells vegetables to the community. Currently she is in a relationship and her partner is HIV negative. She got into the relationship recently and the partner stays in an area which is far away from where she stays, so they do not see each other regularly. She tested HIV positive in 2003 and that is when she started taking the ARV treatment. Participant D is affiliated to the Apostolic Faith Mission. The ARV treatment site is located about 3km from where she stays, so she walks to get there.</p>
Participant E	<p>Participant E is a mother of five children and three of them have passed away. Her first husband left her when she disclosed to him that she is HIV positive. She is currently in a relationship with another man who is a widower and is also HIV positive and on ARV treatment. Participant E dropped out of school in Grade 7 and she sells cigarettes, chips and maputi (roasted corn) for a living. She complained that the profit she got from the sales is insignificant. Her partner does piece jobs, but it is difficult to find them. Participant E discovered that she is HIV positive in 2006 after she developed a wound on her private parts which did not heal. She started taking the ARVs the same year. She walks to the provincial hospital to get her treatment, although it is far from where she stays. She and her partner stay in a kitchen that is divided with a curtain. The house which they stay in belongs to her</p>

	<p>uncle and they struggle to pay a rent of \$30 per month. She is not affiliated to any denomination.</p>
<p>Participant F</p>	<p>Participant F is a widow who is the breadwinner in the house. She is taking care of her three children and her husband passed away in 2004. He was hiding his HIV status from her. After the death of her husband, her in-laws brought her back to her family; she stays in a rural area in a three room brick house. She completed her Form 4 and did not pass well. She is working as a domestic worker at a local school. She discovered her HIV status in 2006 after she had fallen ill and she started taking ARVs the same year. Participant F reported that she is not in a relationship with anyone and is not looking forward to having one in the future. She goes to ZAOGA church. She collects her medication from the provincial hospital which is stationed about 24km from her rural home. She commutes every month to get her medication and she pays \$4 for a return trip.</p>
<p>Participant G</p>	<p>Participant G is a single mother of six children from different fathers. Three of her children are now independent. She does not have a stable place to stay because her mother allegedly chased her out of the house due to her HIV status. She is currently living with her nephew and his family in a rural area. She stopped schooling in Grade 7 and she is not working. She is struggling to fend for her three younger children and she lost contact with her partner when she was pregnant with the child that is now 9 months old. She collects firewood or cuts grass for thatching and sells it to the people so that she can get money to pay the children's school fees and also buy them stationery. Participant G collects her treatment far away, about 35km from where she stays, and she spends days walking to get to the ARV treatment site. She does not get support from her close family members. She discovered that she is HIV positive about a year ago and that is when she started taking the ARV treatment. She goes to a Roman Catholic church.</p>

Participant H	<p>Participant H is a widow; her husband passed away in 2002 of meningitis. The couple had one child who was born HIV positive and this child passed away in 2009 when she was eight years old. Her in-laws chased her out of her matrimonial house after the death of her daughter and she is now renting a three room house in a high density area. She is not in a relationship with anyone at the moment and she is not looking forward to having a partner. She passed four subjects in her Form 4 and could not go further with her studies. Participant H did Advanced Home Based Care training and she assists HIV-infected people in the community who are bedridden. She is a volunteer Nurse Aide for the Red Cross Society. She also does piece jobs such as ironing people's clothes and she sells vegetables to earn a living. Participant H discovered that she is HIV positive in 2005 and she commenced ART in 2006. She goes to Wesley Methodist church. She collects her medication from the ARV treatment site which is within walking distance from her house.</p>
Participant I	<p>Participant I is a widow; her husband passed away in 2003 due to HIV/AIDS. She was the second wife in a polygamous marriage. She did not go to school due to her family's poor background, but she can read and write. Participant I is a mother of eight children, who are all independent and live far away from her. She stays in the urban area, renting a room in a high density suburb. She discovered her HIV status in 2003 when she developed a wound on her anus which was not healing. She initiated ART in 2006. Participant I survives on selling juice cards (airtime) illegally for a living. She goes to Zion church and her grandchildren visit her and support her emotionally. She is not in a relationship with anyone at the moment and she prefers to stay single. Participant I collects her medication from the nearby ARV treatment site which is about 15 minutes' walk from her house.</p>
Participant J	<p>Participant J's husband left her in 2010 after she disclosed her HIV status to him. She is a mother of two children, who are now adults. She</p>

	<p>lives in a rural area in a four room brick house which is sparsely furnished. Participant J lives with her six year old granddaughter and her two year old niece. She dropped out of school when she was in Form 2 and she is not formally employed. She survives by doing piece jobs such as weeding other people’s land and also cleaning their yards. People will pay her in cash or give her groceries and she relies on subsistence farming for survival. She also gets maintenance of \$98 for her two year old niece; the mother of the child has left for South Africa to look for a job, leaving the child in the care of Participant J. She was diagnosed with HIV and TB in 2010 and immediately started taking the TB course for 9 months, followed by the ARVs. She goes to GRM church. Participant J travels about 24km to the ARV treatment site and she pays \$4 for the transport.</p>
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The profiles of the participants above indicate that most of the HIV positive women are living in dire poverty. Those that are married or in a relationship are financially dependent on their partners for support. Some are doing menial jobs to survive such as washing and ironing for other people, cleaning houses or yards, and selling wares. Some ARV sites are located far away and they have to use money for transport to get there, and money is already a big challenge. Those without money will have to walk long distances to get to the sites. Despite the distance, all the participants make an effort to make sure that they get their ARV treatment regularly.

### **3.5.2 Presentation of Themes and Sub-themes**

Themes and sub-themes that were derived from the transcribed interviews will be presented in this section by means of a thematic analysis. Direct quotes from the interviews will be used to support each theme and sub-theme. The majority of the quotes will be in English, with a few Shona statements – these are distinctive as the interviews were conducted in Shona and translated into English. The identified themes and sub-themes will be supported with literature.

Themes and sub-themes derived from the data are as follows:

**Table 3: Themes and sub-themes**

<p><b>Theme 1:</b> Information regarding HIV and AIDS</p>	<p><b>Sub-themes:</b></p> <ul style="list-style-type: none"> <li>➤ Understanding HIV and AIDS and the causes thereof</li> <li>➤ Negotiation for safer sex</li> <li>➤ Partners getting tested</li> </ul>
<p><b>Theme 2:</b> Information on ARV treatment</p>	<p><b>Sub-themes:</b></p> <ul style="list-style-type: none"> <li>➤ Importance of adherence to ARV treatment schedules</li> <li>➤ Purpose of ARVs</li> <li>➤ Side effects of ARVs</li> </ul>
<p><b>Theme 3:</b> Societal and HIV positive women's views on HIV and AIDS</p>	<p><b>Sub-themes:</b></p> <ul style="list-style-type: none"> <li>➤ Disclosure</li> <li>➤ Stigma and discrimination</li> <li>➤ ARV treatment and politics</li> <li>➤ Traditional and faith healers' diagnosis of HIV and AIDS</li> </ul>
<p><b>Theme 4:</b> Experiences of being an HIV positive woman</p>	<p><b>Sub-themes:</b></p> <ul style="list-style-type: none"> <li>➤ Access to medication for HIV-related OIs</li> <li>➤ Consultation fee and buying drugs for OIs</li> <li>➤ Good nutrition and access to clean water</li> <li>➤ Availability of ARV treatment sites and the proximity to these sites</li> <li>➤ Accessing the ARV treatment sites</li> <li>➤ Time spent at the ARV treatment site</li> <li>➤ The availability of ARV regimen</li> <li>➤ Change of ARV regimen</li> </ul>

	<ul style="list-style-type: none"> <li>➤ Referral for diagnostic assessments</li> <li>➤ Support from the family and community</li> <li>➤ Availability of health care workers</li> <li>➤ Attitude of health care workers</li> </ul>
<b>Theme 5:</b> Needs identified by HIV positive women	<b>Sub-themes:</b> <ul style="list-style-type: none"> <li>➤ Adequate antiretroviral treatment</li> <li>➤ Sufficient ARV sites nearby</li> <li>➤ Adequate treatment from health care workers</li> <li>➤ Food</li> <li>➤ Income generating projects</li> </ul>

### 3.5.2.1 *Theme 1 and Sub-themes: Information regarding HIV and AIDS*

<b>Theme 1:</b> Information regarding HIV and AIDS	<b>Sub-themes:</b> <ul style="list-style-type: none"> <li>➤ Understanding HIV and AIDS and the causes thereof</li> <li>➤ Negotiation for safer sex</li> <li>➤ Partners getting tested</li> </ul>
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Commonwealth Secretariat (2002:29) asserts that “[b]ecause of social pressures and cultural norms, women may also have limited access to information about HIV/AIDS, sexuality and reproductive health.” For the HIV positive women to adhere to ARV treatment, they need to understand what HIV and AIDS are, as well as what the causes are. Their husbands or partners’ willingness to get tested and to practice safer sex is also of paramount importance.

#### **Sub-theme 1.1: Understanding HIV and AIDS and the causes thereof**

**Participant A:** ...*They said HIV/AIDS can be contracted through having unprotected sex. It is a disease that can be contracted after a combination of, what can I say? (Sigh). It is only that sometimes you tend to forget some of the information. They said HIV is a combination of various diseases; they come together and form one thing that is called HIV. It is caused by*

*having unprotected sex or using a razor blade that has been used by an infected person after he/she cut himself or herself. If a person that is not infected uses that razor, he/she can be infected.*

**Participant F:** *HIV/AIDS is caused by a virus called HIV. It is contracted through having unprotected sex, or not using gloves when handling an HIV patient who has been injured or has a cut, then the virus can be passed on to you. Most elderly people do not use gloves when caring for their HIV positive children and this will lead to them contracting the disease. Using needles used by HIV positive people can also lead to the transmission of HIV/AIDS.*

**Participant H:** *HIV is a combination of diseases and it can be transmitted through having unprotected sex and also sharing a razor blade. Also if I take care of the wound of someone who is HIV positive without gloves and I have a cut on my hands, I can be infected as well.*

### **Discussion of Sub-theme 1.1**

The participants seem to have a comprehensive understanding of the disease. All the participants have illustrated their understanding of HIV and AIDS and the causes thereof. HIV is a virus and AIDS is a combination of diseases. The literature states that “[t]echnically AIDS is not a single disease, since AIDS patients have many diseases each with their own signs and symptoms. When the body cannot produce a sufficient number of immune-specific cells, it becomes very vulnerable to infection, which leads to terminal illness” (Messer, 2004:xix). The participants might not understand the medical description of HIV and AIDS, but they do understand the disease in simple explanations. All the participants have indicated that they know the causes of HIV and AIDS. It can be contracted through having unprotected sexual intercourse or sharing unsterilized razor blades or needles, and a child can be born with the disease. Knowledge of the disease will go a long way to ensuring and increasing adherence to ARV treatment.

### **Sub-theme 1.2: Negotiation for safer sex**

**Participant A:** *This is a very difficult case for me (Haa ipapo pane nyaya). It is easy if it is a man who tested positive first, not you. ...He says that he is HIV negative. Then I say, fine you are HIV negative, but use condoms. He totally refuses to use them. ... He says if we die we can die as a couple. As for him he does not care about it.*

**Participant B:** *He refused to use protection during sex. He was saying that he cannot use a condom because he married me and paid lobola for me. I was always asking him to use a condom, but he was very adamant. He says he cannot use a condom because I am his wife.*

**Participant I:** *He did not agree to use a condom; he wanted to have sex without using protection (vaingoda feya feya). He was saying condoms are for prostitutes, and I am his wife whom he has married. He was saying he cannot eat a sweet in its plastic paper (handidyire sweet mubepa maro). The nurses told us to use condoms, but my husband was refusing to use them. It was a big challenge on its own.*

**Participant J:** *My husband totally refused to use condoms during sex. He was not interested in it, even if he was HIV positive himself. Even today he does not want to use protection. ... Yes this is one of the reasons he moved out of the house. I also told him that I no longer love him; I am now focusing on my family so it was better for us to part ways because we could die soon. I had also reached a stage where my health was not good. I was sick most of the time. He did not tell me that he was leaving the house, he just left quietly... I told him that if he is not interested in using protection when sleeping with me, he can leave the house. I told him that I thought he wanted us to protect ourselves from re-infections and live positively together, but he did not want to listen to me.*

### **Discussion of Sub-theme 1.2**

The above responses indicate that negotiation for a safer sex is a big challenge to many women. All the participants who were married or in stable relationships indicated that it was very difficult to negotiate for safe sex with their partners. As Participant B and I stated, their husbands refused to use protection on the grounds that they have married them and have paid *lobola*. The literature also states that many women for whom *lobola* has been paid understand that they have been bought; she now belongs to the man and his family and even her sexuality belongs to the one who gave the *lobola* (Phiri et al., 2005:122). Men are not willing to use protection. In terms of the Health Behaviour Theory as discussed in Chapter 2, unsafe sex is a risky behaviour and is harmful to the health of HIV positive women. Insisting on condom use is a big challenge for women and as a result they succumb to their husband's sexual desires even if it is precarious to their health. Women's economic dependence on men, cultural factors and even the threat of violence make it difficult for them to say no to unwanted and often risky sexual intercourse; they are unable to insist on condom use (Commonwealth Secretariat, 2002:27; Pratt, 2003:196; Stine, 2013:338). Men are controlling; they are the ones who dictate what should and should not be done in marriages. Karim and Karim, (2010:483) highlight that "HIV positive people should practice safer sex in order to reduce the transmission of mutants that are more virulent or have developed antiretroviral resistance." The issue of negotiating the use of condoms is still disturbing and many HIV positive women are submissive to their

husbands. Only a few women, like participant J, are able to stand up for their rights and force their partners to use protection.

### **Sub-theme 1.3: Partners getting tested**

**Participant A:** *He says he has gone for the tests and they show that he is HIV negative. I said since you do not have HIV, why are you not afraid to have unprotected sex with someone who is HIV positive? You do not want to use a condom or even let me use a female condom, so it is like you are now an HIV carrier who infects others because as a carrier you cannot have the virus but will supply it. ... He usually goes on his own and will tell me that he has gone for the tests and that he is HIV negative. Recently he called me and said he is coming from VCT at Gomo Hospital, he has gone for the tests as I have suggested and it was discovered that he is not HIV positive and he even donated his blood. When he came here this month, I said it is better for us to go together and get tested; we do not have to go to the doctors, let us use the public clinic because it is for free. He then said no, he has been tested recently, he was told to be tested again after 3 months. ... I am not sure because I have not witnessed it and I have not seen his results after he came from the test.*

**Participant B:** *I went with him so that he could be tested and the results came back negative. I ended up giving up accompanying him to VCT clinic. He was now going on his own. He even went and had his blood tested with those big machines which they say they will trace the virus in the blood, but still it was found that he is not infected. ... I am not sure if he was taught that even if he is HIV negative he still has to use protection when sleeping with me. I think this contributes to my sickness because I can feel that my body is not yet strong; I am ill.*

**Participant G:** *I do not know if he has been tested or not. You know what men do. Sometimes he will be on ART, but he will not be open with you because they want to fix you...*

**Participant I:** *My husband was hiding his HIV status until his last days; that is when he disclosed it. ... I disclosed my status to him as soon as I came from the hospital. What I can say is that I had a dream when his penis turned into a snake. I told him about the dream and when I slept with him my vision was fulfilled; the sex was very painful to me and I went to the hospital after that. I was told by the nurses that I am HIV positive. During sex, I felt like a log was being shoved into my vagina. I was given medication at the hospital. ... I told my husband about my HIV status and soon after my disclosure he was no longer staying in our matrimonial home; he was spending most of his time with his girlfriends. When I told him, he did not seem to be surprised; he said it was my own business (hamenowo zvenyu). ... He neglected me and he was no longer coming home regularly.*

**Participant J:** *What happened is that his cough was excessive and non-stop. He would spend about 1 hour coughing without stopping. I asked him what the problem was, but he did not give me a clear answer. I later saw some bottles of medication in his bag and I took down their names. I took them to the clinic and asked the nurse to explain the purpose of those pills. The health care worker Z told me that they were ARVs taken by an HIV positive person and he asked me where I got the pills. I told him that I found them in my husband's bag and he said it implies that he is HIV positive. He asked me about his whereabouts and I told him that he had gone to town. He then instructed me to go home and check in that bag if there are any clinic cards and I told him that they were there. He said go and get them as soon as possible. I came home and I found a TB card and the one for HIV/AIDS and they explained to me that my husband was HIV positive. ... He (husband) was even telling me that the pills were for his coughing, little did I know that they were ARVs. ... The nurse asked me not to ask him about it or discuss the issue with him. He advised me to come and get tested and after that I would ask him (my husband) to accompany me to the clinic and get tested. If he refused I would then disclose my status to him, laying the blame on myself and see how he would react. I did the same, getting tested, asked him to come to the clinic so that we could be tested and he refused. I told him my status and he said that was none of his business, he does not care about it. I asked him to go and get tested and he refused and that is the way we got separated. I never told him that I had seen the ARVs in his bag and to this day I have kept it a secret.*

### **Discussion of Sub-theme 1.3**

The quotes above indicate that most of the participants' husbands or partners were not willing to get tested. Those that did get tested did not disclose their status to their wives; they kept it a secret and had unprotected sex with them knowing they will infect them. Literature supports this experience by stating that some men get tested privately and start ART without sharing information with their partners. They take advantage of their partners by insisting on unprotected sex (Mahoro, 2005:6). Participant A and B's husbands seemed to be discordant partners or HIV carriers; the virus could not be detected in their blood, yet they do not want to use condoms with their wives. According to literature, "[m]en are more efficient at transmitting HIV to women than women are to men, and women are biologically vulnerable to infection than men" (Pratt, 2003:196). HIV positive women are more than willing to disclose their statuses to their partners, unlike the men. Some participants are not sure whether their partners have been tested or not. Men are not willing to have their partners accompany them to VCT

centres; their status is their secret. There is secrecy regarding male partners getting tested and many women are kept in the dark.

### 3.5.2.2 Theme 2 and sub-themes: Information on ARV treatment

<b>Theme 2:</b> Information on ARV treatment	<b>Sub-themes:</b> <ul style="list-style-type: none"> <li>➤ Importance of adherence to ARV treatment schedules</li> <li>➤ Purpose of ARVs</li> <li>➤ Side effects of ARVs</li> </ul>
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The main aim of this theme is to understand HIV positive women's views on the importance of adherence to the treatment schedules of ARVs, the purpose of ARVs, and the side effects of ARVs.

#### **Sub-theme 2.1: Importance of adherence to ARV treatment schedules**

**Participant A:** *The knowledge I gained is about ARVs. ... They said you will take them for the rest of your life. If you want to take them at 7 o'clock or at 8 o'clock, you should stick to that time every day. You do not have to stop. I take them twice a day. ... I take them at 8am in the morning and at 8pm at night. ... They usually say if you take them without eating food, they will make the soldiers weak. They will still be weak because of the pills you have taken earlier, so if you take another pill before eating, it will weaken them more and they will not be strong. But some encourage us to take them after having food. As for me, I prefer taking the pills before eating anything. ... Yes we have been taught to stick to time. ... Yes they specified a time range to take the pills. You will only have to choose the time which is convenient for you, so you can work and do all sorts of things and make sure that by 7pm you will be home to take your pills. Also they encourage you to carry your medication with you whenever you travel. Do not assume that you will be back early; you have to carry a handbag with the pills everywhere you go. If you cannot get water to drink the pills with, use your saliva to swallow the pills.*

**Participant D:** *We were taught to stick to our time of taking the pills. They said if you skip taking the pills for a day or so, you will trigger the multiplication of the virus. You have to take the pills regularly, don't take them today and skip taking them tomorrow; you should stick to your time. Even if you are going to a funeral, carry your pills because it is not allowed to borrow pills from other people. You should take only the pills given to you. ... As for me when the sun goes down, I will know that it is the time to take my pills. I take my pills at 6am and*

6pm every day. It is the first thing to do before I leave home in the morning and even when the sun is set, I take them as well.

**Participant G:** ... I was told to keep the timetable of taking my pills. Even when I visit I should go with my supply which is adequate. When I do not have my pills, I should not borrow from someone even he/she takes the same pills as me, and I should not lend my pills to anyone. I am given my supply which should last until my review date so I should not share with anyone.

**Participant J:** ... The health care workers also taught me that I am supposed to keep the time of taking my medication, be clean all the time, eat a well-balanced diet, and not to be angry or stressed even if someone provokes me because my CD4 count can go down. ... for the ARVs, I was also taught that if you take the pills at 7 o'clock in the morning, you have to take them at 7 o'clock in the evening again so that the pills will work together. It will also prevent the pill from eating the flesh inside your body because it has not found the chemical it is supposed to mix with. You have to make sure that you eat and take your pills according to your body's requirements... As for me I make sure that by 7am I take my food in small quantities, even soft porridge (*ndodya porridge shoma shoma*), and take my medication. In the evenings I will prepare my supper after having taken my medication at 7pm. I will eat the supper and make sure that I do not move a lot. I find a place to sit, even on my bed in the blankets, waiting for the pills to be absorbed into my blood system.

### **Discussion of Sub-theme 2.1**

This sub-theme on the importance of adherence to ARV treatment schedules was a significant one. Almost every participant commented on the importance of taking their treatment every day without skipping and sticking to the treatment schedule. Literature supports the participants' views as it indicates that patients who are well-informed about their therapy are more likely to feel in control of their illness and are more likely to be adherent, because they understand the reason behind treatment and appreciate the consequences of poor adherence (Arrehag, De Vylder, Durevall & Sjoblom, 2006:384). The participants have indicated that they know the importance of adherence and keep to the timetable of taking their treatment. One has to carry one's medication wherever one goes and should not share it with anyone else. Literature also supports what participant A and J have stated regarding the issue of ARVs with food. Most of the drugs which are taken on an empty stomach are absorbed into the system faster, but it can also cause side effects and some drugs need to be taken together with food so that they are slowly broken down to reduce the side effects (Stine, 2013:74). HIV positive women will have to take their ARV treatment before or after eating food, depending on the

type of drug given to them. Adherence is very important; the treatment needs to be taken consistently without skipping a day.

### **Sub-theme 2.2: Purpose of ARVs**

**Participant A:** *They said it is not curable because the pills we give to you is not to destroy the disease, but to weaken the virus so that it will not keep on multiplying. They said we are not giving you the pill to end the disease.*

**Participant E:** *From the information I have gathered, the disease is not curable. The purpose of the pills is to decrease the multiplication of the virus. Some people are saying in the future a pill will be found which you will take once and be cured.*

**Participant F:** *HIV/AIDS cannot be cured; the purpose of the ARVs is to reduce the multiplication of the virus in the body. ... My body was not like this, but when I started taking ARVs my body changed a lot. I am looking better now....*

**Participant H:** *We are told that the purpose of ARVs is to decrease the intensity of the virus. We should go and have a CD4 count check. I am supposed to go; maybe I will go tomorrow. My previous CD4 count results showed that I had 1500mm<sup>3</sup>/cell and last month they referred me to have another CD4 count check. I can see that my white blood cells are going up and the virus is decreasing and I do not know if it will be destroyed completely.*

### **Discussion of Sub-theme 2.2**

As the participants indicated in this theme, there is no cure for HIV and AIDs and the purpose of the ARVs is to slow the progression of the disease. The literature states that “[t]he main aim of antiretroviral therapy is to delay or prevent the progression to AIDS and death of HIV-infected patients” (Karim & Karim, 2010:529). All of the participants have shown to have a good understanding of the reason for taking ARVs. Pratt (2003:376) goes further stating that “more and more patients with HIV disease are living good-quality lives for a previously inconceivable longer period of time, thanks to the breathtaking advancements in antiretroviral treatment.” ARVs are life-saving drugs to HIV positive people, if they are taken correctly and consistently. The discovery of ARV treatment and its advancement has brought some hope to HIV-infected people. Participants F and H indicated that they have changed dramatically after taking the ARV treatment and their CD4 cell count has increased. Most of the participants have witnessed positive results after taking the ARVs, something which motivates them to adhere to their treatment. Commitment to Highly Active Antiretroviral Therapy (HAART) is for life

(Pratt, 2003:363). Once the infected person starts taking ARV treatment, she has to take it for the rest of her life.

### **Sub-theme 2.3: Side effects of ARVs**

**Participant B:** ... *Yes there are many effects caused by the change of pills. Right now I am having problems with my legs and have bouts of headaches. I am not sure now if I will be fine or not. My feet are burning and sometimes I feel like soaking them in cold or hot water. I do not sleep at night; I stay awake the whole night...*

**Participant D:** ... *The new pills given to me cause me to have cramps and a prickling sensation in my legs. Sometimes when I am walking with slip-ons (shoes), they slip off and I walk on without feeling anything. I have to wear closed shoes all the time to avoid such incidents. I also have recurring headaches and if I go back to the nurses to complain, they tell me that those are the side effects of the pills. They assure me that the side effects will end, but I have been having these side effects for a long time and they are not improving at all.*

**Participant E:** *I no longer have side effects. I used to get cramps in my legs or a burning sensation as if I have stepped on fire. My muscles were also stiff and it was very painful to stretch them, but now I no longer feel it. ... I did not go back to the nurses or doctor to explain my problems; my mother told me that those were the side effects of ARVs. They say many people are no longer adhering to treatment because they say the pills cause cramps, headaches or increase appetite. We were encouraged not to stop taking the pills despite their side-effects. The pills I am taking now make me want to eat a lot of food, but due to lack of food in my house I spend the whole day sleeping waiting for supper time. ... These pills also make me horny; I feel it sometimes, but I control myself. My boyfriend is a bit old so we no longer have sex often.*

**Participant J:** ... *There are some effects from the pills they have given us last month and this month. If you do not take them at the same time you experience pain in your whole body. But if you stick to the time schedule you will not experience any problems. If you want to take them at 9 o'clock, you have to stick to that time. If you wait until 9:05 or 9:10, you start feeling the pain. The ones I am talking about are the ones we were given last month and this month.*

### **Discussion of Sub-theme 2.3**

The quotes above show that the side effects of ARVs are unbearable and this might affect adherence to the treatment. The literature supports what participants have shared by stating that the common side effects of ARVs include nausea, vomiting, diarrhoea, headache, rash, paraesthesia in the hands and feet leading to peripheral neuropathy, anaemia, loss of energy

and mental and sleeping disturbances (Heywood, Band, Ullum, Barford, Silomba, Foster, Whiteside, O’Grady, Fuglesang, Dover, Hammarskjöld, Egoro, Collins & Rau, 2004:61; Pratt, 2003:383). Throughout the interviews, it emerged that most of the participants go back to the clinic or hospital complaining about the side effects and they are not given anything to ease the pain. They are told that the problem will end on its own. Some participants have no hope that the problem will ever come to an end. The participants were told beforehand by the health care workers about the possible side effects of the ARV drugs. The literature states that “[p]atients should be counselled about the milder side effects that they can expect in the first few weeks or months on ART” (van Dyk, 2012:118). Some of the participants were already prepared for the possible ARV side effects. It seems even after taking the treatment for some time, most of the participants are experiencing side effects from ARVs and this is a challenge on its own as it might affect their adherence to the treatment.

**3.5.2.3 Theme 3 and sub-themes: Societal and HIV positive women’s views on HIV and AIDS**

<p><b>Theme 3:</b> Societal and HIV positive women’s views on HIV and AIDS</p>	<p><b>Sub-themes:</b></p> <ul style="list-style-type: none"> <li>➤ Disclosure</li> <li>➤ Stigma and discrimination</li> <li>➤ ARV treatment and politics</li> <li>➤ Traditional and faith healers’ diagnosis of HIV and AIDS</li> </ul>
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The way society views HIV positive women is different depending on their way of understanding HIV and AIDS. Disclosure, stigma and discrimination, and the way the traditional and faith healers diagnose the disease have been shown to have an impact on the women’s access to ARV treatment.

**Sub-theme 3.1: Disclosure**

**Participant B:** *I disclosed my status to my mother first. ... I did not tell her the same time I was diagnosed with the disease; I waited for some time before disclosing it to her. I later called her after she heard that I was not feeling well and I told her about my HIV status. She came to see me and stayed with me for some time. But by then I was in denial; I had not accepted my condition and I was in distress. My husband told me that he loved me despite my HIV status. My husband is the one who took me for VCT, so he was the first one to know that I am HIV*

*positive. ...When he discovered that I am HIV positive he started isolating me. At times he would feel bad about the way he was treating me, because he was the one who infected me with the disease. He later fell in love with my step-sister whom I called to my house to take care of me when I was sick. ... (After disclosure)- I felt that I had removed a heavy burden from my heart. I felt much better, but my husband's family did not take the news lightly; they were not impressed by my status. Even now, they dislike me and blame me for the disease. My mother-in law was later diagnosed with HIV/AIDS as well. ... My husband is the only child in her family, so his mother said that if her son dies I am the one who has caused his death. They said that I am HIV positive because I was promiscuous and I asked them to show me this boyfriend they claim I have, but they failed to show me. They asked me how I could be HIV positive when their son is HIV negative.*

**Participant F:** *I did not disclose my status to my family. I only told one person and that is my aunt. ... She did not take it lightly; she was hurt as if she was the one who was diagnosed with the disease, but I had accepted my status. ... When I tested positive, I accepted my status but my aunt found it hard to accept it because she thought I would die; she was stressed. I did not find it hard to accept my status. I knew that I have to take my pills regularly. HIV/AIDS is just like any other disease. People with high blood pressure survive on pills, so am just like them. I was counselling my aunt and even advised her to go and get tested since she was a widow, so that she would know her status. ... I did not disclose my status to the family because I was afraid that they will tell people about it or even use it as a weapon against me whenever I have a clash with them. I only disclosed to my aunt and my friends who are also HIV positive. Sometimes when you are at a meeting or a gathering, some people will say "you HIV positive people (imi varwere), go in front and have your names written down" and it lowers my self-esteem. They would say it loudly in front of the crowd and it really hurts because I did not choose to have my condition. It is like having people insult you because of your disability; you fail to understand what they are implying regarding your condition. I got the disease when I was faithful to my husband; it is not like I was promiscuous. It is like a diabetic or hypertensive patient, you just get the disease without knowing it. This is the reason I do not want to disclose my status to other people.*

**Participant H:** *I was very happy to know my status. The counsellor was even shocked with my reaction; at first she did not want to tell me the results. I asked her to tell me the truth and I told her that I was very happy to know my status because many wives of my husband's colleagues passed away not knowing their status. The husband would pass on and the wife would follow within a short period of time. ... I told my sister-in-law, Mrs Xxx because it was*

*difficult to tell all the people. My mother separated from my father and married again. She stays far away from me. It is difficult to disclose your status to everyone because they will not keep it to their hearts. I trusted my sister-in-law; I went to her workplace on my way back from the hospital. She accepted it and encouraged me to follow the instructions given to me. ... I felt relieved after disclosing my status to my sister-in-law. I later on told my father and mother after some time. I was afraid that my mother would be stressed thinking that I was going to die soon. When I told her, she said “you did a good job my daughter, these days you should not leave things unattended; I would have lost you by now”. My father also appreciated my courage in getting tested and also that I was open to him about it. Other people like my brothers and relatives could have spread my status to the people. During those days when I started taking ARVs, people were pointing fingers at us and it was very disturbing. When you wanted to go to the hospital to collect your supply, you could see people looking at you with glowing eyes and you could tell they were discussing your status, so it was not easy for us to live openly. This led me to decide not to disclose my status to the people I thought were going to spread it to the community. ... Now my brothers know my status because some of them are also on ART. My father asked me to go and encourage my brothers to get tested and start ART. One of my brothers passed away because he was in denial; he did not want to take his medication.*

**Participant I:** *I disclosed my status to my daughter first. Last year I disclosed my HIV status to my family (2012). I used to hide my status due to fear of stigma and discrimination. People used to think that they could contract HIV/AIDS through sharing a cup with an HIV positive person, greeting them or sitting close to them, so I did not want my relatives to discriminate against me.... I was taught that you cannot contract the disease through greetings, sharing a cup even spitting your saliva; that is why I decided to tell my family. ... My family is now well-informed about the disease, hence no stigma and discrimination. I am now the one who encourages them to get tested and come out with their status so that they can get help. ... My daughter accepted my status since she had knowledge about the disease. ... I felt relieved after disclosing my status and it became easier for me to take my pills openly without hiding them. Many people know my status because I tell them the truth. I have buried many people who did not want to disclose that they were HIV positive.*

**Participant J:** *Yes, I have disclosed my status to my family. I told my son – he came to visit me because he heard about my ill health. I told him and even showed him my clinic cards. ... I told my husband first the moment I came from the hospital. He was not impressed with the news; it was my son who took care of my medical expenses when my husband left me. ... When I told my husband about my status, he changed the way he was relating to me which shows that he*

*was not impressed at all. Yet he was also taking ARVs secretly. That is when he left the house; he is now staying at the resettlement farms. ... I became relieved after disclosing my status to my husband and son; I felt at ease with my condition. I also began to see other people who have the same condition as me. People were now asking me about my welfare, stating that I am now looking fit and active. I am now advising them that if you feel your body aching and feeling weak or even if you have eye problems, you should go to the clinic and get tested. You might have been infected with HIV, you do not have to waste time, go to the hospital and get tested whenever you are not feeling well. Many people come to me and say “what you have said is what I am feeling” or “that is how my child is feeling”. I then say “let us go to the clinic and have the person tested”. When we get to the clinic, the person would be diagnosed with TB or HIV/AIDS. Disclosure has helped me to deal with my condition and it became easy to walk around and interact with other people. I even told my relatives that if I die at any time, they should not waste their time consulting with prophets and traditional healers regarding the cause of my death; it means my time to die has come.*

### **Discussion of Sub-theme 3.1**

This sub-theme discussed the period of disclosure to partners, family and community, the first person the participants talked to and the feelings experienced after the disclosure, as well as the reaction expressed by the person disclosed to. From the quotes above, it shows that disclosure requires a greater level of trust. Most of the participants stated that when they first disclosed their status it was to the people close to them, be it a mother, sister, son or daughter. They knew that those people whom they confided in regarding their HIV status were not going to spread the news to the community. Literature states that HIV-infected people have to carefully weigh their decision about when and how to tell someone about their HIV status and who to tell it to (Derlega & Barbee, 1998:3). Most of the participants took some time before they disclosed their HIV status to their families and to the community at large.

Some of the participants indicated that they were neglected and deserted by their husbands after their disclosure and some were accused of being promiscuous. The literature supports what the participants have shared by stating that spouses, particularly wives, are frequently deserted upon disclosure of their HIV status (Ogden & Nyblade, 2005:31). Disclosure is a difficult decision for some HIV positive women to make, because it is often followed by major life-changing consequences. It has been found that some participants took their time to disclose their status to the family or the community at large. The reason for procrastinating was fear of

stigma, belittlement and also labelling. This finding is supported by Heywood et al. (2004:30) who mention that in Southern Africa, those who are HIV positive often do not reveal their status for fear of being socially ostracized, abandoned or subjected to physical harm. Commonwealth Secretariat (2002:31) goes further stating that in cases where men are not tested, women tend to be blamed as vectors of the epidemic (to partners and children) even if it is the husband who has passed the disease to the wife. She may be labelled promiscuous, abused, abandoned or even killed and the man may seek to re-marry a younger woman who is HIV negative, who he will expose to HIV infection as well. Some participants commented on their husbands leaving them for other women and that they were accused of promiscuity.

Most participants reported that they felt relieved after disclosing their HIV status to the family and some to the community. Their families never judged them; instead they supported them on their journey of living positively. Literature supports this as it refers to numerous families where after disclosure of a member's HIV-positive status, some of them come together, offered sympathy, support and care and sometimes contributed funds towards the monthly purchase of antiretroviral drugs (Brown, Trujilo & Macintyre, as quoted by Siyam'kela, 2004:5). Disclosure has helped some of the participants to take their treatment openly and they are now able to help some HIV-infected people who are in denial. However, there are some participants who do not want many people to know their status and they have only disclosed it to a few close family members.

### **Sub-theme 3.2: Stigma and discrimination**

**Participant D:** *I have never noticed discrimination from this community because people are working together. We have never heard people saying HIV positive people should sit on their own; we do everything together with HIV negative people. There is no longer finger pointing because people are now informed about the disease. We are now concerned about diabetic people because their condition is very risky, unlike ours. But during the first days it was very difficult because people were discriminating against us and wherever you went people were pointing fingers at you saying "this one is HIV positive".*

**Participant E:** *There is a lot of discrimination going around here. You hear other people saying "those ones are people for ARVs". They say HIV positive people are not normal; they are mad people you should not listen to them. People do not take your opinion or contribution seriously because you are HIV positive. Even if we are at gatherings or funerals, you notice that some people are not pleasant towards you. They will be annoyed thinking that I can infect*

*them with the disease through interacting with them. They look down on us, not wanting us to associate with them.*

**Participant F:** *People segregate us HIV positive people. If we go to gatherings, they will not allow us to cook or prepare the food because they think they will contract HIV through the food. There are areas where we are not supposed to work, like cooking, cleaning the dishes, etc. There is discrimination because some people do not know their status; they mock us telling us that “she is not the one who gave me the disease”. They insult us in different ways. ... I keep quiet, but I am hurt inside.*

**Participant G:** *At my mother’s place people were discriminating against me. They think that they can be infected with the disease through talking to me or sharing a plate with me. People are not happy to sit around you, they avoid you. Even if you try to have a conversation with them, they will just show you that they are not interested in talking to you or they will tell you a big word that will hurt you. I remember one day I was told that people who take ARVs are troublesome; they are crazy and they cannot be listened to. This taunted me; I was thinking that taking ARVs meant that I am now a mad person, I am horrible, stinking or I am failing to do things which show that I am a normal human being. I was told this statement by a relative. My family even chased me out of the house. This implies that they are saying “with your condition if you die, who will bury you?” or “if you get seriously ill, who will take care of you?” People do not want to take care of an HIV positive person, especially when she develops ulcers or wounds and this is the reason my family deserted me. They want me to die far away from them.*

**Participant H:** *Stigma and discrimination was prevalent a couple of years ago. You know during those days, even during the funerals people were no longer shaking hands; they were just saying “big up” and it was weird. One would feel uncomfortable; people were thinking that one could get HIV/AIDS through shaking hands with an HIV positive person. ... The people I socialize with know about HIV/AIDS so they do not discriminate against me. It seems discrimination against HIV/AIDS people is now coming to an end even at churches. My child passed away in 2008 when she was doing Grade 4. When she was alive I was really hurt when she wanted to play with other children at church and their mothers would beat them and prevent them from playing with my daughter because she was HIV positive. This hurt me until one day I told them that HIV/AIDS is not transmitted when your children play with my HIV positive daughter; the disease is in the blood. I told them that you are confusing and disturbing my child and make me, as her mother, feel uncomfortable about coming to church. They changed their perception from that time. I even disclosed to my Pastor about my HIV status.*

*Stigma is still prevalent now because some people think that you got the disease through prostitution. Your in-laws also think that you are the one who gave their son the disease and there will be hatred. There are some people who look down on us because they do not understand the disease. Even at churches some people will not want you to lead them when taking the Holy Communion.*

**Participant I:** *Nowadays people see HIV positive people as human beings; they treat us with dignity. But some look down on us, even the health care workers. If you give your opinion, even if it is a fact, they will say “no, we cannot listen to this one who takes ARVs”. They will say “these people (HIV positive people) know nothing”. They assume that when you take ARVs you are not able to give any meaningful contributions. People do not want to listen to your opinion. ... They say HIV positive people are crazy because of the pills they take, which disturbs them mentally. I will tell them that we are better than them; we take the pills because we know our status unlike those who are not taking the pills and are afraid to get tested. High blood pressure can disturb the mind but not HIV/AIDS.*

### **Discussion of Sub-theme 3.2**

It seems as if the quotes above reflect that the participants had mixed feelings about the existence of stigma and discrimination in their respective communities. Some of the participants indicated that stigma and discrimination are still prevalent; people point fingers at HIV-infected people. They feel as if they are social outcasts at public gatherings when people do not want them to assist with cooking or washing the dishes. Literatures supports these comments by stating that HIV positive women do not only face the dilemma of illness, but are also subjected to social rejection, discrimination, breach of their confidentiality and other violations of their rights (Messer, 2004:60; Stine, 2013:350). Ignorance, denial, fear and intolerance in some communities lead to stigmatization and discrimination.

The biopsychosocial model asserts that the person’s physical, emotional, social, cultural and economic situation has an impact on his/her adherence and access to treatment. “HIV/AIDS challenges the patients’ body image and identity and their sense of self-image, their social and familial relationships and life roles are also affected”, (Spies, 2007:163). People who are HIV positive are often disgraced publicly or personally and, as some participants have stated, they are seen as crazy people and their opinions are not listened to. According to Heywood et al. (2004:30) “from the onset, the HIV epidemic has been accompanied by an epidemic of fear, ignorance and denial, which has led to stigmatization of and discrimination against people with

HIV/IDS, their family members and certain groups perceived as morally deviant.” HIV positive people are looked down upon as indicated by some of the participants. They feel that they are not respected and people ridicule them because of their status. As participant F has stated, people insult them in different ways and she will keep quiet but will be very hurt by their statements. Heywood et al. (2004:31) further states that “the stigma and discrimination that accompanies HIV/AIDS only serves to amplify personal pain and suffering and to increase despair and guilt, resulting sometimes in depression or suicide.” When the community views HIV positive women as crazy people and also refuse their assistance during the public gatherings, this damages their confidence and self-esteem.

On the other hand some participants indicated that discrimination was prevalent a couple of years ago, but nowadays people seem to be well-informed about the disease. Literature also supports this finding as it states that an increasing number of people are deciding to get tested and seeking more knowledge on HIV and AIDS. As there is an increasing access to ART, the stigma of HIV and AIDS will be less in future years (Arrehag et al., 2006:44). People are now tolerant of HIV positive women in some communities and they involve them in the social activities. To support the participants’ different comments, Messer (2004:61) states that acceptance and understanding prevail in certain circles of society but there is enough antipathy and discriminatory practices that have remained in which revealing one’s HIV-positive status is still a traumatic experience. Different communities view HIV positive women differently, depending on their level of understanding of HIV and AIDS and their level of tolerance as indicated by the above quotes.

### **Sub-theme 3.3: ARV treatment and politics**

**Participant C:** *No the ARV treatment is not affected by the political situation in the country; we are getting our supply every month.*

**Participant D:** *We have never encountered it. We are not allowed to even wear political regalia when we go to collect the pills at the clinics. The supply of ARVs is not linked to politics and when given the pills, they do not give us according to our political party saying “this one is for MDC” or “this one is for ZANU PF”. We get the pills openly; they do not want political regalia there. If you have a saru for a certain political party, they will tell you to go back home and leave it and come back to collect your pills later.*

**Participant F:** *Haa, we have never encountered any problem, there is no link between politics and ARV treatment.*

**Participant H:** *I think from what I have heard, our President is the one who sourced the ARVs from outside the country for us to survive. So as for me, I think there is a connection between ARV treatment and the country's political situation. If it was not for him, there would have been few people left in the country; many people would have been dead by now. ... No we have never met any violence or the use of politics in the issuing out of ARVs....*

### **Discussion of Sub-theme 3.3**

All the participants have indicated that ARV treatment is not affected by the political situation in the country. They indicated that they all get their supplies openly, despite the different political parties people are affiliated to. There is no violence involved in the issuing of ARV treatment. The participants' comments contradict with literature, as it indicates that "political turmoil, civil wars, and international conflicts comprise yet a sixth barrier to universal access" (Messer, 2004:145). Despite the political upheaval in the country, the HIV positive women are getting their ARV treatment regularly without any interruptions.

### **Sub-theme 3.4: Traditional and faith healers' diagnosis of HIV and AIDS**

**Participant B:** *I consult with prophets; even yesterday I was there. ... Yes throughout my sickness I was consulting with the prophets and traditional healers. My mother has passed away so they were saying my mother wants me dead because she is seeing the way I am struggling and I said "let her take me". I once threw myself in a well because I was very depressed, wondering how my step-sister could marry my husband and take my children away from me. By then I had not sat down with her and disclosed my status to her, but she knew that I am HIV positive and yet she chose to believe what her husband told her.... When I was consulting with the prophets their remedy was not making my condition better. Yesterday I went there and it made my blood boil when they told me that my mother (who is deceased) said she wants to come and take me and I said "let her come fast". The second wife took my children and she told me that they are now her children; I will never get them back. The prophet assured me that I will get my children back. I once had a terrible headache and was diagnosed with meningitis. That is when my children were taken away from me and the second wife does not want me to have access to them... Yes they (prophets) say my mother wants me dead because she sees the way I am struggling. I was given holy water and the stones. The prophets are not talking about my HIV status; none of them are telling me that I am HIV positive or advising me to go and get tested. Instead they tell me different stories.*

**Participant C:** *When I am not feeling well, I consult with the prophets at my church. They give me holy water to use and I will feel much better after using that water. At our church they do not prevent us from taking ARVs; they allow us to use the pills with the water they give us. Holy water works much better than the pills.*

**Participant D:** *Haa, there is no prophet or a traditional healer who can cure HIV/AIDS. ... There are many cases where you see HIV positive people going to consult with prophets and traditional healers regarding their sicknesses. Some of the traditional healers and prophets are misleading people, especially the upcoming Pentecostal churches; they make people stop taking the pills and think that they are healed of HIV/AIDS. We are burying many people because they have stopped taking their ARVs due to the prophets' testimonies on them. But what I have noticed with some prophets, like prophet P, is that he advises a patient to go to the hospital with her condition, telling her that he cannot assist her. Some prophets are open with people and they encourage them to go to the hospital and get tested. ... Even if you are already on ART, they will treat you by giving you holy water and pray for you, but they encourage us to go to the clinic.*

**Participant F:** *I go to ZAOGA church. There are many people who consult with the prophets and traditional healers, even if one could see that this person is HIV positive. The person would not want to stick to her ARVs and the prophets will give them holy water, assuring them that they will be healed. They will tell them that it is because of evil spirits and eventually the person will die. If you are on ART and you consult with the prophets or the traditional healers, they will tell you that you have no medical problem, it is your late grandmother who is haunting you. They will make you stop taking the ARVs. I even noticed it with my aunt; she was going to an Apostolic church and was told that she was not sick, but that it was her late grandmother who was troubling her. I went to collect her medication from Masvingo General Hospital, but when I came to give them to her she threw them at me saying she is no longer taking ARVs because she was told that it is her late grandmother who is causing this sickness. She threw the pills at me and went to the shrine where she was given stones and holy water to drink. She passed on in 2009.*

**Participant G:** *I go to AFM church. Aaah a person on ART is not allowed to take any other medication. The purpose of their (traditional and faith healers) medicines is to clean dirt from the body. My body was swollen after taking the traditional medicine, but now I am fine. That is when I learnt that you do not have to mix traditional medicines and ARVs because some of the traditional medicines are very strong. You will also create confusion in your body by taking both traditional medicines and ARVs. At the end of the day you will not know which one has*

*worked for you. ... I am not keen to consult with the prophets because sometimes they will tell you that you are having stomach pains because you have been bewitched. As an individual, one should accept her condition because denial leads to people consulting with the prophets and traditional healers.*

#### **Discussion of Sub-theme 3.4**

The spiritual aspect is one of the components of the biopsychosocial model. A belief system or religion helps people to find hope and being involved in a religion leads to a physically and psychologically healthy lifestyle (Carr, 2004:24). It is clear from the quotes shown above that many HIV positive women consult with traditional healers or prophets. The cause of their illness, they are told, is either witchcraft, evil spirits or angry ancestors. Literature supports this finding as it states that debilitating illness and other misfortunes are seen to be as a result of witchcraft or supernatural forces unleashed by the angry ancestors (Ashforth, 2002, in Flint, 2011:14). Some people look at AIDS as punishment from God on an evil society and others see it as a result of witchcraft (Phiri et al., 2005:137). From the quotes above, it shows that some of the participants are taking ARVs and consulting traditional or faith healers at the same time. Many people consult with both traditional healers and western health care workers for the same condition: they want the traditional healers to diagnose the personal cause of the condition, which is believed to be bewitchment, and to perform rituals. The western doctor is consulted to treat the condition symptomatically (van Dyk, 2012:218).

Most of the participants have indicated that the traditional healers or the prophets give them holy water and stones. According to Becker and Geissler (2009:316), “the Zionist and Apostolic healers see themselves as the mediums of the Holy Spirit and they administer remedies such as cooling ash, holy water, strengthening by means of steaming or tying brightly coloured yarn around the body or cleansing with enemas and emetic”. Some participants indicated that they would feel much better after taking the remedies given to them, but some stated that they did not improve and others that their bodies reacted to the concoction. As participant G stated, her body reacted after taking the traditional medicine which was meant to cleanse her body of any impurities. The literature also states that “some of the traditional remedies are in fact dangerous” (Flint, 2011:15). The quotes also show that some of the traditional healers and prophets mislead people by making them stop taking their ARV treatment. They assure people that they are healed of HIV and AIDS and the infected women will stop taking their treatment thereby endangering their lives.

### 3.5.2.4 Theme 4 and sub-themes: Experiences of being an HIV positive woman

<p><b>Theme 4:</b> Experiences of being an HIV positive woman</p>	<p><b>Sub-themes:</b></p> <ul style="list-style-type: none"> <li>➤ Access to medication for HIV-related OIs</li> <li>➤ Consultation fee and buying drugs for OIs</li> <li>➤ Good nutrition and access to clean water</li> <li>➤ Availability of ARV treatment sites and the proximity to these sites</li> <li>➤ Accessing the ARV treatment sites</li> <li>➤ Time spent at the ARV treatment site</li> <li>➤ The availability of ARV regimen</li> <li>➤ Change of ARV regimen</li> <li>➤ Referral for diagnostic assessments</li> <li>➤ Support from the family and community</li> <li>➤ Availability of health care workers</li> <li>➤ Attitude of health care workers</li> </ul>
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The aim of this main theme is to determine the availability of OI medication, good nutrition and clean water, as well as the ARV sites. It also seeks to understand if the ARVs are readily available and what kind of treatment is received from the health care workers.

#### **Sub- theme 4.1: Access to medication for HIV-related OIs**

**Participant B:** *The nurses will not give me pills for other diseases or illnesses. When I started my ART, they told me that they will not give me any other medication besides ART. Right now my legs are so painful and I have headaches. I feel like taking pain killers, but if I go to the hospital and report it they will say “go and take your ARV pills”. It is now useless to go to the hospital complaining of any other disease. When I take my ARVs, the headache will stop but the pain in my legs will be worse.*

**Participant C:** *I get medication for other illnesses. They give me green pills for my womb problems and for the chest pains they give me pink, round pills but I have to pay for those pills....*

**Participant D:** *There is a problem there. They tell us to take ARVs for any pains and they will not give us any medication. If we complain of other illnesses, they will tell us to take cotrimoxazole, but they are no longer giving it to us so we will just take the ARVs. ... No one is receiving cotrimoxazole anymore. Sometimes we complain of chest pains and headaches, and we are told to take ARVs, but the aches persist. When we feel the pains and take cotrimoxazole, we would feel much better. But now we do not have them; we are given ARVs only. They are saying cotrimoxazoles are in short supply; they are only given to those starting ART.*

**Participant G:** *Recently I went to the clinic with chest problems and I was given some medication (coughing). I was thinking of telling the nurses at the hospital when I go for my supply on 29 May that my chest is painful, especially when I carry heavy things....*

**Participant J:** *If you go complaining of headaches they will give you paracetamol. If you complain of anything they will give you medication for that problem.*

#### **Discussion of Sub- theme 4.1**

According to Karim and Karim (2010:479), “[m]orbidity and mortality in HIV is largely a consequence of opportunistic infections that occur with impaired immunity.” The participants gave different accounts of their experiences regarding access to OI medication. Some of them are given the medication and some state that whenever they complain about any other health problems, they are not given any other medication; they are just told to take their ARVs. Literature states that that using ARVs can reduce the incidence rate of opportunistic diseases by around 80% (Karim & Karim, 2010:479). From the quotes above, it indicates that OI medication is given depending on the problem reported by the infected women. Some of the participants indicated that they feel better after taking cotrimoxazole, but now they are no longer receiving it and they are told that it is in short supply. This is supported by literature which highlight that “cotrimoxazole reduces the incidence of a number of opportunistic infections” (Karim & Karim, 2010:485). It seems some of the health problems reported by the participants are the side effects of the treatment, which will end on their own without taking any medication. That is why they are encouraged to take their ARVs consistently.

#### **Sub-theme 4.2: Consultation fee and buying drugs for OIs**

**Participant A:** *We get the ARVs for free, we do not pay any money. For other medication we will be asked to pay for it. ... It depends on your medical problem and the way you have explained your problem. Sometimes you have a cough or chest pains and they will ask you to pay \$3 or \$4 for the medication. If you complain of backache, you have to prepare to be charged \$15 or more. We are asked to buy the medication for opportunistic infections on our own. They say the government does not have money to purchase medication for other diseases.*

**Participant E:** *They can even charge you \$2. I remember I was sick and I went to this nearby clinic where they charged me \$4 for the medication. My stomach was hard and swollen; they gave me pills to take three times a day. If it was not for my mother who borrowed money for me from her friends, I could have been dead by now. My mother is not working and she is struggling to make ends meet. She is the one who assists me to buy medication. She borrows money from her friends and sometimes if she fails to pay it back, she will work for those people for repayment.*

**Participant H:** *That is where the main problem lies. Right now my friend came over in the morning because I am not feeling well. I have a headache and fever, and I think it is malaria. She said "let's go to the clinic" and I told her that at the hospital we can only get cotrimoxazole. If you want any other medication you will have to buy it. ... We pay the normal price that we would at any other pharmacies and it is difficult for us because I do not have money. My friend was even saying that maybe I have malaria and I told her that malaria is not related to OI, so if I go to the hospital they will tell me to go to outpatients where they will want money for a card and medication. They charge \$5 for a card and after the doctor's assessment, they will tell you to go and buy medication from the hospital's pharmacy. This is a challenge to us; they should treat any sickness of HIV positive people free of charge. They say it is only the cotrimoxazole and ARVs which are for free. There was a time when I had eye problems and I went there and was referred to the optometrist who prescribed me tetracycline and I bought it from the pharmacy. I was charged \$3 for the card and \$2 for the medication. This is a big challenge to us because sometimes you fall sick when you do not have the money. I am sick right now but I cannot go to the hospital because I do not have the money for the card and medication.*

**Participant J:** *Yes we do pay money for other drugs especially if you go to this nearby clinic. ... We pay \$2 and a child is charged \$1. For the ARVs we do not pay anything, they are given for free. If you complain of other ailments, they will tell you to go and buy the medication from the hospital pharmacy. We will go to the pharmacy with the prescription and there you will be*

*asked to pay \$3, \$4 or \$5 depending on the medication. Sometimes they will not have the medication in stock, so you will end up buying it from private pharmacies.*

#### **Discussion of Sub-theme 4.2**

Mahoro (2005:23) states that “[a]lthough treatment programmes have been initiated in most countries, often the focus is on ART and individuals have to pay for treatment of opportunistic infections.” It is clear from the quotes above that the infected people are only given ARVs and cotrimoxazole drugs for free; they are expected to pay for any other medication prescribed to them. It has been reported that the government says it does not have money to buy medication for other diseases. Messer (2004:142) reiterates that “while many treatment discussions primarily focus on anti-retroviral medications (ARVs), many ill people lack even the most basic medicines and treatment.” From the quotes above, it seems many HIV positive women are afraid to visit the health care centres while presenting other health problems because they will be asked to pay money for the card and also for the prescription, even though they do not have any money.

As participant E stated, if it was not for her mother who lent her money for her medication, she could have been dead by now. The literature also states that “[b]eing ill and poor, one must rely on one’s relationship-one’s family position and value-as well as one’s ability to convince-often by any means necessary-to obtain the money for a medical visit or treatment” (Becker & Geissler, 2009:361). Getting money to pay for consultations and to buy the medication seems to be a very big challenge to many infected women. Participant H stated that she was sick on the day of the interview, but could not go to the clinic because she had no money to pay for the card or the medication. Commonwealth Secretariat (2002:28) states that “worldwide, there are increasingly more poor women than men, a phenomenon commonly referred to as the ‘feminisation of poverty’.” Many of the participants are struggling; they find it difficult to purchase the medication prescribed to them and as a result some prefer to stay at home without visiting the health care centres with their health problems.

#### **Sub-theme 4.3: Good nutrition and access to clean water**

**Participant A:** *The government is not involved in providing patients with a well-balanced diet; they say we have to cater for ourselves. ... Donors say they are not coming here to give food to HIV positive people only. They say we have to provide for ourselves. They do not even consider the HIV status of people when giving them food. If you do not have money, it means*

*you cannot afford good food. You have to eat what there is to survive. If there is no money, there is no money; you have to deal with what there is (unodealer nezviripo). If there is no cooking oil, you have to eat sadza (pap) with salted water and life goes on (kudya munyu nemvura nesadza). ... We do not have a borehole; we draw our water from the wells. We do not boil the water; we just drink it straight from the well. We have never encountered any problem with our water.*

**Participant B:** *We used to get food donations until the hospital decided to check our CD4 count first before we are given the donation. Only people with a CD4 count below a certain figure were given food and they are very few now. Our CD4 count was above the required figure and we were taken off the list. ... There is no food, people are struggling. My husband sends me money sometimes if I ask him. Yesterday I called him asking him to send me money and he said he will send some, so I am still waiting for his deposit. ... We have clean water; we get it from the borehole.*

**Participant D:** *It is difficult to eat a well-balanced meal. We are struggling to put food on the table. Most of the times we eat pap and vegetables and when we find money we can buy fish. I am not working and it is very difficult for me to find money. We cannot even find traditional food. We survive by buying everything; this year is a dry period and we did not get anything from the fields. We buy maize meal or mealie meal from the shops, depending on the money we have. Sometimes you sell vegetables and get \$6. A bucket of maize meal costs \$10 so you will be forced to buy a small bag of mealie meal. Red Cross used to give us food but it has stopped now and many HIV positive people are dying because of hunger. ... We get clean water from the borehole.*

**Participant E:** *We cannot get the food. We just go to our friends' places towards meal times and will eat there. Some people are no longer willing to give us food to eat when we get to their houses. We once went to our friend's house and when she saw us coming she took the pots off the stove and we just left still hungry. When we arrived home, I asked my mother to lend us a cup of mealie meal so that we could prepare food for ourselves. Normally we visit other people's houses during lunch times to eat there and we will eat supper at our house. Red Cross used to give us plenty of foodstuffs. Now they have stopped, saying their donors have pulled out. ... Water is there, but we once had a water cut and it went on for 3 days. We were getting water from the boreholes which are a bit far away. When the water comes back on, it will be very dirty and we drink it as it is without boiling it.*

**Participant H:** *I was taught what kind of food to eat and that we have to exercise. There is a diet chart at the hospital; they say we should eat food rich in proteins, carbohydrates, vitamins*

*and mineral salts. I am into small farming activity. I planted maize there last season and I got 3×50kg bags, but the thieves stole some of the yield. I do not eat a well-balanced diet. Traditional food is especially difficult to get. It is compounded with the shortage of rainfall; people are not getting anything from their fields. I like eating traditional foodstuffs but I do not get them. ... We get water from the tap and if there are water cuts, we get our water from the boreholes. We often experience water cuts and when the water comes back it will be very dirty. Last time when it came back, it was very dirty and rusty and I just thought we were going to die. I advised other people to boil the water first to avoid getting diarrhoea. There were others who were saying they do not have time to boil it. They would decant it by leaving it overnight in a bucket and the following day all the dirt and rust will be at the bottom of the bucket.*

### **Discussion of Sub-theme 4.3**

This sub-theme of good nutrition and clean water was a significant one. Almost all the participants commented that they are struggling to make ends meet, let alone eating a well-balanced diet. Literature states that HIV infected individuals have higher nutritional requirements than normal; they have to maintain their body weight by eating a balanced diet, especially high-protein calorifically dense food (increased by up to 50%) and energy (increased by up to 15%) (Barnett & Whiteside, 2002:22; Pratt, 2003:325). Most of the participants indicated that they are not working, while some were involved in small gardening businesses and some lived off subsistence farming. There was a dry spell in 2012 and 2013; they did not harvest anything from the fields. Literature supports this comment by stating that Zimbabwe is currently experiencing a severe shortage of food due to the severe drought the country has experienced in recent years, coupled with the chaotic Land Reform Programme which has led to the departure of experienced farmers and capital (Rupiya, 2006:160). Poor people are faced with the challenges of unemployment and food shortages.

Those on ARV treatment are not sure if they will have regular and nutritious meals which are necessary for taking their medications and boosting their immune system, and this affects their already compromised immune system (Stillwagon, 2001 in Rohleder et al., 2009:98). This supports participant E's statement that they are not sure where their next meal would come from; they usually visit people's houses around lunch time so that they could get food, but sometimes they are turned down. Rohleder et al. (2009:93) further states that "unequal distribution of resources, such as education and limited opportunities, may force certain groups to menial jobs." As indicated on the participants' profiles, most of them are not well-educated.

They are unemployed and survive on odd jobs such as washing and ironing for people, weeding other people's fields, vending or subsistence farming, or rely on their husbands for support. Eating a balanced diet seems to be a luxury to them, not a real need given their health condition. It is not because they do not want good nutrition, but because they cannot afford it.

Regarding access to clean water, the participants have different experiences. Some participants stated that they got their water from the wells and boreholes and it is clean enough for drinking. Those who got their water from running taps indicated that they experienced water cuts and when the water came back it would be very dirty. Karim and Karim (2010:482) highlight that "access to safe drinking water is very important, as many agents causing debilitating diarrhoea in HIV infections are waterborne." Some of the participants indicated that they drink dirty water straight from the tap without boiling it and some stated that they decant it. Literature states that tap water should be boiled first, cooled and stored in a refrigerator and it should be prepared daily (Karim & Karim, 2010:327). This is against what most participants are doing; some drink straight from the tap and some only boil the water when it is dirty after the water cuts.

To conclude discussion on this sub-theme, Messer (2004:144) reiterates that "[h]uman hunger and lack of food security are a daunting challenge to make ARVs effective. People cannot take powerful medicines without proper and dependable diet or on an empty stomach." From the quotes above, it shows that the availability of good nutrition is a big challenge to almost all participants. This in turn will have an impact on their access to ARV treatment, because it is difficult to take the medication on an empty stomach and some ARVs also increase appetite. Poverty is reigning its terror in the lives of HIV positive women.

#### **Sub-theme 4.4: Availability of ARV treatment sites and the proximity to these sites**

**Participant C:** *I collect my pills from Masvingo General Hospital. It is far from where I am staying and I have to use transport to get there.*

**Participant D:** *It is very close here at Takavarasha. We walk about 2.5km to get to the treatment site. We collect the pills on Tuesdays – the dates they give us fall on a Tuesday. The sites are few because you find people coming from Mabika (12km), Cheteni (10km) and Chisenga and Chiware (17km) to collect their supply here. Some people do not come regularly due to the distance and also lack of transport money. When the health care workers call their names they are not present. People leave their house at 4am and walk so that they can get to*

*the treatment site early because the health care workers from the hospital arrive here at 10am.*

....

**Participant F:** *We get our ARV supply from Masvingo General Hospital which is about 24km from here. The ARV sites are very few in this area.*

**Participant H:** *Once when we were collecting our supply at the General Hospital we were transferred to the grounds because it was too crowded at the hospital. The OI clinic is too small to accommodate the increasing number of HIV positive people needing ARVs. People are now collecting their supplies from the clinic in their areas. I think it is now better. Here we have Mucheke Clinic, Runyararo Clinic and people from Rhodene go to the General Hospital. ... Today I even asked another man why he is collecting his pills from the hospital when there is an ARV site (clinic) closer to him. He said he goes to the hospital because he is afraid that he might not find the pills he is taking at the clinic. I explained to him that the pills we get from this clinic are supplied by the same hospital. People are not well-informed about the link between ARV sites and the hospitals; they just assume that one day they might not find their supply at the clinic. ... Some people might not want to be seen by their neighbours going to the clinic nearby to collect their ARVs. Some lie to their neighbours, saying that they are going to town when they are going to the hospital for their supply....*

**Participant I:** *The ARV sites are available and where I am collecting my supply is not far from my house. I used to get them from the General Hospital and was later transferred to Mazorodze Clinic which is nearby. There were many people who were collecting ARVs from the General Hospital so the nurses said if we have a site near us, we can tell them and they will transfer us there. I told them of Mazorodze Clinic and they transferred me there. ... Some people do not want to collect pills from their nearby clinics because they are afraid to be seen by other people going to the clinic. Some are afraid that they will not find all their pills there and there are no doctors at the clinic. If there is any problem you will be referred to the General Hospital...*

#### **Discussion of Sub-theme 4.4**

The quotes above reflect that the participants had mixed opinions regarding the availability of ARV treatment sites and their proximity. Some participants stated that the sites are few and are located far away from where they are staying. Mahoro (2005:6) states that “[m]ost health facilities are far from where people live and most women either have to travel long distances or pay large amounts of money in transport fares to access treatment.” For some participants the ARV treatment sites are closer to their homes and they stated that some people opt to go to the sites that are far away from them for fear of disclosure and discrimination. Literature does

not support this, but from the researcher's viewpoint it seems that some HIV positive people have the perception that district or provincial hospitals have ARV stocks all the time and hence they do not want to go to the smaller sites closer to them. They prefer to go to the hospitals even if they are very far from them.

#### **Sub-theme 4.5: Accessing the ARV treatment sites**

**Participant A:** *We have two clinics in our area, but we do not collect our supply there. We go to Masvingo General Hospital (24km from the area). That is where the main problem is (ndiplo pane dambudziko ipapo). We sometimes do not have money for transport to get to the site to collect our medication, yet we have a clinic nearby. We pay \$2 to and \$2 from the hospital in order to get our supply. The ARV sites are far away from where we are staying. I am given a date to come and collect my supply and the date will be in the middle of the month. I won't have money and will be forced to skip taking my pills because I will be busy looking for transport money to get to the site. We just go to the clinic for minor ailments such as flu and you will pay for consultation. If it is a serious illness, you will have to look for money to go to Masvingo and see a doctor.*

**Participant B:** *The site is about 4km from home. I will walk to get there due to lack of money. When I get there I find many people already in the queue. ... I leave the house at around 6am and get there around 10am.*

**Participant C:** *I pay \$1 for two way transport or R4 to and R4 from. I have to look around for transport money so that I can go for my supply. I rely on my husband to give me the money and sometimes he does not have it. He will be waiting for the end of the month when he gets paid. This time I am going back for my supply on the 15<sup>th</sup> of May. They give me a one month supply.*

**Participant G:** *I use \$10 to and from the hospital. The problem is transport money. When I do not have the money, I walk and sleep over at my daughter's place and proceed to the hospital the following day. I walk 23km to my daughter's place and then walk about 10km to the hospital. I leave the house at around 5am and get to the hospital at around 8:22am.*

**Participant J:** *We travel by kombis or private cars to get there and we pay \$2 for a one way trip. In that case you will struggle or go for some time without medication, unless you can run around and borrow money from other people. We normally do not walk to get there. ... No, I have never skipped my supply date. If I do not have money, I make sure to borrow it from other people whilst I still have the supply. I will pay back the money when I get the maintenance money.*

### **Discussion of Sub-theme 4.5**

The quotes above indicate that participants access ARV treatment sites through various means. Some of the participants walk for long distances due to lack of money. Literature supports the participants' experiences by stating that "Furthermore, poor individuals may have difficulty paying for transport to their points of ARV collection and may struggle to access their medication regularly" (Rohleder et al., 2009:98). From the quotes above, it shows transport money is a big challenge to many HIV positive women. Some have to wait for the end of the month when their partners get their salaries, even though their review date is mid-month. Some have to borrow money from their neighbours so that they can travel to the ARV sites. According to Arrehag et al. (2006:63), "[n]ot all households have the necessary cash reserves to meet the increasing expenses related to HIV/AIDS illness that consume both cash savings and assets. In this situation, some resort to borrowing." The transport money reflected above ranges from \$1 to \$10, which is quite exorbitant for unemployed HIV positive women.

### **Sub-theme 4.6: Time spent at the ARV treatment site**

**Participant A:** *You will find so many people there; the queue will be very long (unowana pane line rinonzi line). You will go to one office, then come back to the line and go to another office and stand in a long queue. You will stand in the nurse's line and from there you will join another long line to collect medication. ... You wait there for a long time. You can leave there around 11am or 12pm or even at lunch time. The first line is for stamping the card and there you will be given your file. After that you will go to see a nurse where they will question you about your condition and how you are feeling. They will also write down the medication to be given to you if you complain of other ailments. You will not be given the medication they prescribe for you for free; you will have to pay for it at the hospital pharmacy. From the nurse we go to the pharmacy for ARVs and from there you will go to the general pharmacy for other medication for backache, side pain or so on. This pharmacy is separate from the ARV one and has its own queue. ... Yes we can spend 6 to 7 hours at the hospital. The benches are sometimes full, so you will have to sit down if you have a saru but if you do not have one you will stand most of the time.*

**Participant B:** *I will spend the whole day at the hospital and leave there around this time (4pm). ... The healthcare workers take their time; they are very slow with their services. When they go for their break time, they will not come back. If they go for their lunch break, they will leave you sitting on the bench waiting for them to come back. We have our own section for HIV positive people and it is difficult to be served there....*

**Participant C:** *There will be long queues at the hospital; there are many people who are coming to collect ARVs. Usually I get there at 9am and by 11am I will be served. Sometimes I will leave the hospital after 4pm depending with the queues on that day.*

#### **Discussion of Sub-theme 4.6**

The researcher found that almost all of the participants commented on the long queues at the ARV sites. It has been stated that the participants leave their homes very early in the morning and still find very long queues when they get to the treatment sites. Literature supports this comment as it states that people have to wake up very early in the morning and wait for hours in very long queues before they are served (Campbell et al., 2011:181). Some participants commented that the services they receive from the health care workers are poor. They reported that the health care workers leave them sitting in the queues while they go for their extended tea break or lunch. From the quotes above, the researcher understood from the participants that long waiting hours in the lines coupled with the slow service delivery is a frustration to them. This is in a way a challenge to the women's access to ARV treatment, as some clients might avoid going to collect their treatment because they dread to wait in long queues. This is the researcher's opinion; the literature did not specify it.

#### **Sub-theme 4.7: The availability of ARV regimen**

**Participant A:** *... That problem is persisting. When we get our pills, you find that some bottles or boxes are missing inside the big box. Let me show you a big box (she went to collect the box from her bedroom). You will be given a big box like this and they say you do not have to open it in front of them (nurses). You will open it when you get home and that is when you will discover that some of the pills are missing. ... Usually you find an opened box. It will be like this (showing and demonstrating a closed box to the researcher). You will be given two big boxes like this. This supply is for two months (pointing at two big boxes). Right (sigh), you will be given your two boxes like this and your cotrimoxazole. They say you do not have to open the boxes there. You will just open, removing this thing (instruction paper) when you are at the pharmacy. ... Yes you just open the box, but you do not have to check what is inside. You will check when you get home. You might be given a big box like this and these two small boxes will be missing. A big box has 10 small boxes inside. It means someone has stolen them. You can only find eight small boxes. A small box has three days' supply of pills. It is difficult for us to go back to the clinic and tell them that we have discovered some small boxes missing from the big boxes that were given to us. They will not believe us. ... We have started opening the*

*boxes in front of the health care workers now after experiencing this problem. Now we are clever. We have realized that you might receive an empty box or a box with missing pills or with three small boxes inside. Now we open it there and if there are pills missing you return the box there and then. .... These are some of the challenges we face. As I have said, one small box lasts for three days. So if two boxes are missing this means you will spend six days without taking your pills and you are not allowed to go back to the hospital before your review date. This is a challenge because you will go for days without taking medication until your review date. ... Yes it affects our adherence because we are supposed to take medication every day. I will go for several days without taking my medication until I get to my appointment date. ... They will not give you a new supply before the review date. They assume I have the supply. They might also think you have sold the pills. This is another challenge we experience.*

**Participant B:** *We do not get the same type of pills. They tell us that some types of pills are not found at most clinics. In my case, I take TDF pills. They say if I want to transfer to another clinic, I should go to the clinic where I want to be transferred to and check if they do have that type of pills in their stock. When I get there they will ask me reasons for my transfer and ask me several question like the ones I was asked when I started ART.*

**Participant H:** *Sometimes we get only one type of ARVs. When I went there (clinic) last time, I was told that fevarenz is out of stock and that I have to go to the hospital. This will disturb me psychologically because I think that I am now going to die because my type of pills is not available. They say there are a certain number of people registered for ART here and they are given the quantities for those people. But there are instances where someone comes from outside town visiting her relative and will be short of the pills, so she will go to the clinic and they will give her pills. She might say she had come to visit her relative here in town and she overstayed and her supply days have passed, her pills are finished. The nurses will give her pills because they are not allowed to refuse giving ARVs to an HIV positive person in need of them. This implies that they are taking from the counted quantities and will make it short. These pills are like diabetes pills; they need to be taken daily and consistently.*

**Participant J:** *... In 2010 they used to give us the same type of pills. But now we do not even understand. You find them in different colours and shapes every time, some in bottles or boxes. Sometimes we also find the pills missing inside the boxes or bottles. They tell you that they have given you a two months' supply, but when you get home you find some boxes missing. The nurses will not count for you. She will ask you to take your box and leave her office and you open the box when you get home. ... No they will not replace those pills if you go back to them. They will say you have to get a new supply. They will not replace the missing ones. That is*

*where the challenge is. They will give you a month's supply and you will realize that the pills are about to finish before the end of that month and you will not have money to go back for a new supply.*

#### **Discussion of Sub-theme 4.7**

ARV distribution is a vital aspect in the management of HIV and AIDS, as the life expectancy of HIV positive people hinges on their access to ARVs (Flint, 2011:87). When one looks at the above quotes it seems as if the participants experienced stock-outs and also ARV theft, although it is not very significant. Some of the participants stated that when they get to the treatment site, they are told that their specific pills are not available. It seems there are ARVs which are difficult to find because they are expensive and also because they are produced in limited quantities. Literature supports this finding as it states that cost is considered to be a critical factor in the rollout of ARVs and about 97% of people receiving treatment in low-and-middle-income developing countries are receiving first-line ARV therapy; second-line therapies are more sophisticated and less toxic, but are prohibitively expensive (Flint, 2011:148). Even if there are decreases in some ARV prices, some companies continue to assert intellectual property rights to limit the production of cheaper generic substitutes of key drugs (Development Update, 2004:216). The shortage of ARV drugs disturbs the infected women; some of them panic, thinking that they are now going to die as stated by participant H.

Some participants indicated that pills go missing from their boxes, but that they do not have money to go back to the site before the end of the month. It seems there are people who are stealing the pills from the boxes. The participants are given boxes which are short of few pills, because the health care workers do not count or check the contents with the participants. It will be difficult for the participants to convince the health care workers that they were given ARVs which were short and some participants will end up going for days without their medication, waiting for their review date to come.

#### **Sub-theme 4.8: Change of ARV regimen**

**Participant B:** *They keep on changing us. Currently I am taking TDF pills and the previous month I was taking another type together with cotrimoxazole. They do not explain to us the reason for changing the pills and they will not even tell us that they have changed the pills....*

**Participant E:** *They are changing them a lot. We were once given a pill that was yellow on one side and white on the other, then we were changed to long, pink ones and this time we were*

*given the long, yellow ones and long, blue ones. ... They do not explain to us the reason for changing the pills. The nurses tell us that even though they have changed the pills it does not mean that the virus is destroyed. If we ask them many questions, they will tell us that we should take them like we were taking the old ones. I once got confused with the ever-changing pills and I did not know how to take them. I was used to taking one pill from the bottle and now there were two bottles and they said you should take two pills in the morning and one in the evening. They also said I could take them the way I normally took the previous supply and that is where I got confused. I took the pills back to the clinic and another nurse explained to me that I take two pills from one bottle in the mornings and one blue one in the evening, and that is when I understood.*

**Participant F:** *I started with Stalanev 40 and changed to Stalanev 30. Now I am taking another type of ARVs. ... No, I am not experiencing any effects, I still feel the same. They explained to us the reason for changing the pills. They told us that Stalanev 40 was in short supply and that is the reason why everyone was moved to Stalanev 30. They said anyone facing challenges with the change of her medication can be moved back to Stalanev 40. Those of us who have been on ART for so many years have been moved to the new ARVs we are taking at the moment. They say the dosage was combined to make it one pill. For example if you were taking two pills in the mornings they can change it and you will take one pill in the morning and one pill in the evening. A person who used to take TB pills and a person who has never had them get different ARVs. ... The colours of the pills may change, but the name will be the same. They explain to us about the colours of the pills and the times of taking them.*

**Participant H:** *I am not happy with the way they keep on changing us pills. I was comfortable with one pill, milon, which I was taking in the evenings. They say it has many drugs in it and will make a person drowsy. Last month they changed my pills and I was told that milon was out of stock even at the hospital. I even asked the people who collect their supply at the hospital and they told me that they were also told the pill was out of stock. I was given two types this time. I take one type in the morning and the other type in the evening. ... I have never seen any changes, they work the same.*

**Participant I:** *I have no effects to the pills, they are good for me. But the change of the pills is a problem because it can disturb our health. I was used to taking one pill in the evenings and now I have to take pills in the mornings and evenings. They say the change of pills is due to the change of machines which make these pills. The colours of the pills have also changed. The one I am taking in the morning is blue and white and the one for the evening is yellow in colour. I take cotrimoxazole in the morning as well.*

### **Discussion of Sub-theme 4.8**

The researcher found that all the participants commented on the constant change of their ARV drugs. From the way the participants narrated their experiences, their ARVs are not changed from the first-line regimen to the second-line regimen, which is expensive. Most of the participants stated that the ARVs given to them monthly are different in terms of shape, colour and quantity. Sometimes they are given one type and sometimes two types of the drugs. The participants have different views regarding the constant change of ARVs. Some say it is because of stock-outs and others stated that it is because of the different pharmaceutical companies which manufacture the drugs, but that they are the same ARVs.

The reason for change of ARVs does not correlate with literature, which states that the occurrence of drug toxicity, the person's intolerance to medication despite adequate and appropriate treatment, and virological failure are indications that the antiretroviral drugs need to be changed (Karim & Karim, 2010:529; van Dyk, 2012:119). From the quotes above, none of the participants indicated that they developed drug toxicity or virological failure because of the drugs given to them. Their ARVs are just changed without them developing any problems, reactions or complications to them. Some of the participants are not impressed with the way their ARVs are changing and this affects their confidence and trust in the treatment. Some of the participants are confused; they do not know which pills and how many to take per day, in the mornings and in the evenings. It seems the constant change of ARV types has an impact on the HIV positive women's access to ARV treatment, because some were used to taking one pill per day and now they have to take two pills or vice versa. They can easily forget to take the pills or to stick to the instructions.

### **Sub-theme 4.9: Referral for diagnostic assessments**

**Participant D:** *It has been a long time since I last went for review. I last went for review when I was in Bulawayo. Is it what they call CD4? I last went to Bulawayo in 2009, but they (nurses) do encourage us to go for a CD4 count check. They do not force us to go for review. In most cases you will just go on your own wanting to know how far you are with the disease. They do it here at Takavarasha if electricity is available, because sometimes there will be power cuts, and it is for free. They do it for the ones coming for the first time and there will be long queues. You will have to rush back to the children you have left alone at home. They refer us for CD4 count at the hospital, but the problem is we do not have money to travel there. Sometimes when you get to the hospital, you find their machines are not working or there are power cuts which*

*means you will not be served that day and will have to go back home empty handed. ... No the nurses will not force us to have a CD4 count review. They encourage us to go for diagnostic assessment but due to lack of money we will keep on postponing going to the big hospital.*

**Participant F:** *We are referred for a CD4 count check after six months. Most of the time the machines at the hospital will be busy. They give preference to the first timers. We will be forced to go to the New Start centre if we are not going there for the first time. There is only one machine available so they consider those who are coming for the first time. Sometimes the machine will not be working at the hospital. We pay \$1 at the New Start centre to have the tests done and there will be long queues there, so you should arrive there by 6am. They will spend 20 minutes with one person for the results to come out. If you are number 15, you can be served around 2pm or 3pm. ... You have to plan a day for the New Start centre and a day for the supply. You have to find ways to get money to pay at New Start centre because at the hospital they will not assist you without CD4 count results. They will want to see if the pills are helping to boost your immune system. ... At the hospital they do a CD4 count check every Wednesday before 11am; you will be served if there aren't many first timers on that day. You go to the New Start centre because there the results come out at the same time, unlike at the hospital where the queues are very long and you wait until 2pm to get the results. It is difficult to wait until 2pm due to hunger and fatigue, and if you leave without collecting the results they might be misplaced. Money is a big problem, but one is forced to do piece jobs in order to raise money to travel for a CD4 count check and also to collect your ARV supply. Sometimes we share expenses with another HIV positive person. For example I will give her my card to collect my supply and I will contribute \$2 for transport....*

**Participant H:** *We are referred for diagnostic assessment after six months. Right now I am supposed to go before 15 May; maybe I will go around next week. I last went for my assessment six months ago and now they wrote on my card that I should go back again. ... New Start centre is now doing CD4 count checks. It is frustrating to go for assessment at the hospital because most of the time they say their machines are not working and they have certain days for CD4 count checks. They usually do it on Mondays, Wednesdays and Fridays and you do not get the results on the same day. You will have to go back the following week to get your results. At the New Start centre, you get the results the same day and you pay \$1. There will not be long queues unlike at the hospital. Most of the time you walk to the hospital, about 4km. I usually leave the house at 6am and will get there at around 7:45am. If the queue is not long I can be served at around 10am, but if there are many people I will leave around 1pm. At the New Start centre, they limit the number of people. They take about 15 people per day, so if you get there*

*and see that you are after the 15<sup>th</sup> person, you will just leave because you will not be served on that day. They do not spend the whole day doing CD4 count checks.*

**Participant I:** *We are referred for a CD4 count after every six months. We either go to the hospital or to the New Start centre. Most people go to the New Start centre because there will be long queues at the hospital and you will be told to come back another day to get your results. The reason for the long queues at the hospital is that all people from the rural and urban clinics are referred to that hospital. Sometimes you will be told that the machines are not working at the hospital and they will ask you to come another day. We do not want to waste time because our businesses will be waiting at home. At the New Start centre you get the results within a few minutes. We pay \$1 there, but at the hospital it is for free. Unlike at the hospital where you can spend the whole day in a queue, the queues are short at the New Start centre. When you go back to get your results, you will be told to look for your name on your own and it is a big challenge for us....*

#### **Discussion of Sub-theme 4.9**

Throughout the interviews, it emerged that money is a big challenge for most HIV positive women. Some participants indicated that they last went for their CD4 count check a couple of years ago due to lack of money to travel to the district or provincial hospitals. Literature states that laboratory infrastructure is necessary for HIV-related OIs and to monitor the effectiveness of treatment by checking the viral load and CD4 count. Lack of access to laboratories and prolonged waiting times between tests and results slow the pace of treatment delivery. Health care workers end up using clinical markers such as weight loss or gain and those not showing clinical markers are referred for the laboratory tests (Development Update, 2004:219; Heywood, 2004:218). Because there are no laboratories at small ARV sites, especially in the rural areas, the nurses are using the participants' weight to assess if they do need to change to the second ARV-regimen; it is not compulsory to have their CD4 count checked regularly.

Most of the participants stated that they go for their diagnostic assessment after every six months, but the problem is that there are few machines at the hospital and sometimes they are broken. There are also long queues at the public hospitals. According to Heywood et al. (2004:60), “[t]he lack of laboratory capacity and the high costs, particularly of viral load measurements as well as CD4<sup>+</sup> counts, have been some of the most common arguments against the general introduction of antiretroviral therapy in Africa.” It seems it is expensive to purchase and maintain the laboratory machines for the viral load measurements, hence there are long

queues because all the HIV positive people are serviced by only a few, if not one, machines in the whole hospital. Due to frustrating hospital conditions some participants end up going to a private company which does the CD4 count check, paying \$1. Lack of money is a big challenge; some participants cannot afford that \$1 at New Start centre and they will end up spending years without having their CD4 count checked. This affects their level of treatment.

#### **Sub-theme 4.10: Support from the family and community**

**Participant B:** *All my family members were diagnosed with HIV/AIDS and they became better after being on ART. I believe that I will be well too. ... I do not get much support from my family. They know my problem, but they do not want to support me. My brother is the one who sometimes takes me to the hospital and after I collect my pills I will call him and ask him to come and pick me up from the hospital.*

**Participant C:** *I do not get support from anyone except from my partner. If I am sick, I have to look for someone to cook for me, fetch water and do the laundry and I will pay her. My neighbours help me sometimes when I ask them.*

**Participant E:** *I do not get any support from people. They say they are also struggling; they can support me emotionally through socializing. My mother is the one who supports me emotionally, materially and financially.*

**Participant H:** *My father supports me emotionally and he encourages me to follow the instructions given to me at the hospital. My sister-in-law counsels me, telling me that I should use condoms when sleeping with a man. I have joined a support group at Red Cross; we meet on Wednesdays and Fridays. We encourage and motivate one another. We also have our Stokvel or club whereby we pay \$1 every Wednesdays and Friday. At the end of the year, we will have a party and buy ourselves groceries like sugar, cooking oil, soap, etc. and will share them amongst the members.*

**Participant I:** *I get a lot of support from my children, family and friends. My children are very supportive, they send their children to keep me company and support me materially... I also have another friend of mine who supports me emotionally; she comes for a sleep over at my place when I am not well emotionally and physically. I am also at Kushinga HIV and AIDS Support Group; we meet every Wednesday from 9am to 12pm. There we encourage each other to take our pills on time and for older people, like us, to stay single and the young ones to use protection when having sex.*

### **Discussion of Sub-theme 4.10**

The participants gave different responses on the support they received from their families and the community. Karim and Karim (2010:529) propounded that “[p]oor adherence is the major cause of failure to achieve viral suppression and remains a particular challenge in the developing world, although studies have shown that adherence is possible where patients are supported.” Almost all the participants indicated that they received support from their family members, even if it is only one person who is involved in their welfare. Literature states that “[t]he presence of stable relationships and having access to social and emotional support are also an important factor in maintaining adherence” (Pratt, 2003:384). The main support received from the community is the emotional support.

Besides the emotional support, it seems the support needed by many participants is the material and financial support which they do not get from their communities. Some participants have joined support groups where they share their experiences and they encourage one another to live happily and positively. Literature supports this experience by stating that there are no established networks. Using buddy systems may help to support the patients through the initial stage of therapy, while structured group programmes may provide an opportunity for the construction of more supportive networks (Pratt, 2003:388). The more people come together the more the group becomes solid and stronger. Those participants who have joined support groups seem to have a sense of belonging and they feel comfortable in the presence of other HIV positive women, encouraging each other to take their treatment consistently.

### **Sub-theme 4.11: Availability of health care workers**

**Participant A:** *I can say the health care workers are many, yet they are few. Sometimes it does not help that there are many, because they will all be in one office and spend more time there socializing while we are standing in queues waiting to be served by them. Sometimes there are only two offices working and it will be difficult to change lines to a faster one, because other people will complain. Like the way we are sitting here (demonstrating), this bench should be attended by this office and this one by this office. So if your line is not moving, it is difficult to move to another bench. It means that even if the nurses are many, few of them will be working hard and showing dedication in their work. Others will go for a tea break at 10am and come back after 11am, and she will take her time waiting for lunch time to come so that she can leave the office again. By then the queue will be getting longer and we will be the last ones to be served.*

**Participant C:** *They are few at the hospital. You sometimes find only four workers serving people for the whole day.*

**Participant E:** *The health care workers are many. It is a problem if they go for their tea break; they forget that they have left patients in the queue waiting for them. Sometimes people will end up shouting at them saying they should remember that we are sick people; they should serve us faster so that we can go back to our homes. They (nurses) will even answer back saying we are not the ones who have asked them to come late at the hospital. There will be an exchange of words between the patients and the nurses. They will be busy socializing and their service is very slow. Some might even forget to write people's next supply dates because they are busy talking to their colleagues*

**Participant H:** *The nurses are enough here at Mucheke Clinic. There is no doctor here. If there is a problem which needs the doctor's attention, they will refer you to the General Hospital.*

**Participant J:** *There are few health care workers at Masvingo General Hospital. Sometimes you will find one nurse serving the whole OI clinic and the queue will be very long. We wait for very long hours before we are served, especially at the pharmacy. Due to long queues the health care workers will sometimes not give patients enough time to explain their health problems. They will be rushing to finish the queues. Sometimes you as a patient you will not explain what exactly you feel; you leave some of the details out because the nurses will tell you that they are behind.*

#### **Discussion of Sub-theme 4.11**

Arrehag et al., (2006:126) highlight that “[t]he public sector primarily provides services, and therefore human resources is the most important factor for efficient public service delivery.” The quotes above reveal that most of the participants are not happy with the service they receive at the ARV sites. They have mixed views regarding the availability of health care workers. Some participants stated that the number of health care workers is sufficient, but that the services they provide are very poor. People will wait in long queues whilst the health care workers are busy socializing or while they go for extended tea and lunch breaks, forgetting that they have left patients waiting for them. Some participants indicated that there are few health care workers at their sites and they have to attend to a large number of people in need of ARVs. Literature states that the epidemic has caused an increase in mortality and morbidity rates of health care workers, which leads to high attrition levels, an increase in absenteeism and high vacancy rates. This will result in a greater workload for the employees who are left (Arrehag

et al., 2006:126). There is a shortage of human resources due to poor working conditions, migration of health care workers to private sectors and abroad, and poor remunerations (Heywood, 2004:218). From the quotes above, it seems the health care workers are few and with the ever increasing number of patients needing ARVs, they are burnt out and they lack motivation to render efficient and effective services to the patients.

#### **Sub-theme 4.12: Attitude of health care workers**

**Participant C:** *The nurses are good, they are our teachers. They can be rude at times, depending with the nurse who is serving you that day. They also take time to attend to you; usually they give first preference to their friends and relatives. They can call a person behind you and you will be left waiting in the queue.*

**Participant F:** *They treat us with dignity and they are understanding. Sometimes you can see that the nurse serving you is on ART. They always tell us that there might be some who are HIV positive amongst themselves, so they have to treat the patients the way they want others to treat them. Many of them are very kind; they are only few individuals who have a bad attitude towards the patients. They are only harsh with people if they do not want to cooperate. For example, they encourage people to come in the mornings and if you can get there at 2pm they will be rude to you because by then they will be busy packing the files and returning them where they are supposed to stay. They will serve you after shouting at you....*

**Participant H:** *As I have said earlier on, some of the nurses are our partners. They are also HIV positive. They are very friendly and welcoming. But during the first days before they introduced that system of having HIV positive nurses working at the OI clinic, the experience was not good. The nurses were not patient with us, they were very rude. I was really hurt. Even now when I see that nurse at the hospital, my heart is in pain. I went with my daughter and they wanted to put a drip on her. As a child, she was moving and crying in pain and that nurse said “hold your child tightly; she will infect me with the disease”. I cannot forget that incident and it really touched me. Now the same nurse is on ART as well and you cannot remind her what she told me. She now looks worse than us. When I saw her I asked her if she could remember me and I reminded her that I was P’s mother. Her expression showed that she was embarrassed.*

**Participant J:** *I have noticed that the nurses who have many years of experience treat us well. The junior nurses mistreat patients; they are not patient with patients. ... I received bad treatment from a nurse once when I was admitted at the hospital. When I went for a chest x-ray, the nurse said to the man who was taking x-ray “hey, can you check on that woman*

wearing a red doek and see what her problem is”. The matron overheard her and she called her to her office for a reprimand. I have seen that the junior nurses do not seem to understand and they lack patience with sick people. The senior ones are more friendly and welcoming. ... If I fail to get my supply on a given date, the nurses will give it to me on whatever date I go, but they will not believe your explanations or excuses and some will shout at you.

#### **Discussion of Sub-theme 4.12**

Most of the participants praised the health care workers and they appreciated their attitude. The quotes above show that the health care workers have a positive attitude towards the HIV positive women. They have been described as being good, understanding, kind, patient, friendly and welcoming. It has been reported that most of the health care workers are also HIV positive and that they are on ART themselves, so they connect with the participants because their experiences with the disease are similar. They are more tolerant and understanding. This contradicts with literature which states that “[a]t the treatment level, stigmatization is felt within the health sector where health care workers are insensitive and judgmental in relation to patients who are HIV-positive...” (Development Update, 2004:220). The participants did not deny the fact that personalities are different; not all health care workers are friendly and tolerant. It has been commented that some health care workers are very rude and cheeky and that they treat the patients badly. The junior staff members especially have been reported to be insensitive.

#### **3.5.2.5 Theme 5 and sub-themes: Needs identified by HIV positive women**

<p><b>Theme 5:</b> Needs identified by HIV positive women</p>	<p><b>Sub-themes:</b></p> <ul style="list-style-type: none"> <li>➤ Adequate antiretroviral treatment</li> <li>➤ Sufficient ARV sites nearby</li> <li>➤ Adequate treatment from health care workers</li> <li>➤ Food</li> <li>➤ Income generating projects</li> </ul>
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The participants were also given the opportunity to state their needs as HIV positive women. Heywood (2004:28) states that “[i]ndividuals suffering ill health in Zimbabwe also receive less government support for their needs...” Adequate ARV treatment, sufficient ARV sites and

treatment, food and income generating projects were identified as sub-themes under the needs of HIV positive women.

### **Sub-theme 5.1: Adequate antiretroviral treatment**

**Participant A:** *The assistance needed by people living with HIV/AIDS is a pill which can destroy this virus. Also to be assisted with food and medication that can destroy this disease. ... The education we receive is sufficient.*

**Participant B:** *The sites are many, but sometimes they do not have your type of ARV in stock. You can only get them at few sites and at the hospital. They should have all types of ARVs available to all ARV sites.*

### **Discussion of Sub-theme 5.1**

Some of the participants stated that they wish for a drug which can destroy the virus once and for all. The other participants commented that they wish stock could always be available at the ARV treatment sites, to avoid travelling longer distances to the big hospitals looking for a specific ARV drug. It seems the education received by the participants regarding HIV and AIDS and ARV treatment is adequate; they are given lectures every time they visit the ARV treatment site for their monthly allocation.

### **Sub-theme 5.2: Sufficient ARV sites nearby**

**Participant F:** *To increase the number of ARV sites. Like in our case, if the site is close by we can walk to the site and will not encounter shortages of money to go for the supply. Money is a very big challenge to us.*

**Participant G:** *We want assistance in terms of increasing the sites closer to where people stay, so that they can walk to collect their supply. In my case when it comes the time to go to the hospital I stress a lot about how I will get there. I have to walk a very long distance to get there.*

**Participant J:** *The assistance that is more important to us women is to get ARVs at a nearby site or clinic. At a place where you can go anytime when you are left with even five pills and be back home by 10am. Many women I meet at the hospital come from different places and they will have money to go back home. Some will bring along tomatoes to sell so that they can have money to travel back home. Yesterday I met with another woman who was saying she came the previous day and slept at the rank-in. She had a bucket of wild fruits to sell so that she can have money to travel back home. Many women are struggling financially; it would be appreciated if the sites could be moved closer to us. It save us from travelling long distances*

*to collect the medication. Sometimes you will find other women walking long distances carrying a baby on their backs; it is very difficult for us....*

### **Discussion of Sub-theme 5.2**

Most of the participants commented on the need to have the ARV treatment sites situated closer to where they are staying, that is within a reasonable walking distance. Throughout the interviews, most of the participants reported a lack of transport money to get to the ARV treatment sites. Distance and high costs associated with transport might make patients have difficulty in accessing ART clinics (Harries et al., 2010:62). They highlighted that there is a real need to increase the ARV treatment sites to avoid congestion at the few ARV sites available. Increasing ARV treatment sites and also bringing them closer to people will improve adherence and HIV infected women's access to ARV treatment. They will no longer have to worry about transport money to meet their review dates.

### **Sub-theme 5.3: Adequate treatment from health care workers**

**Participant C:** *We should have nurses and doctors who are kind and patient. Some health care workers are rough and some are good. They should be taught how to take care of patients and their numbers should also be increased at the sites.*

**Participant F:** *We want to be served fast when we get to the site. It is good to receive treatment faster when you visit the hospital. We also want the health care workers to be patient with us and to listen to our health problems, because sometimes they will just say that everyone is having the same problem with their feet so there is no problem with that.*

**Participant H:** *How the nurses treat you depends on your level of friendship with them. I wish they would treat all the people the same without discrimination.*

**Participant J:** *We expect love from health care workers, given our health condition. We expect them to treat us with dignity, be patient with us and not to mistreat us.*

### **Discussion of Sub-theme 5.3**

Some of the participants indicated that as HIV positive women, they request that health care workers be polite, patient, attentive and caring towards them. The participants requested that the health care workers should be trained on how to handle HIV positive patients and to treat them with dignity. Some healthcare workers are also HIV positive and this affects staff availability and morale. Staff shortage and absenteeism increase, thereby weakening the already overburdened health system (Heywood, 2004:219). Some of the participants suggested

that there is a need to increase the number of health care workers at the ARV treatment sites and this will ensure the fast and efficient delivery of services to the patients.

#### **Sub-theme 5.4: Food**

**Participant D:** *We are asking for food, if we can find people who are willing to help us. We used to get food from Red Cross but they said they can no longer afford to assist us. They used to give us a 50kg bag of maize meal, 10kg of beans, porridge, cooking oil, washing soap, blankets and flour.*

**Participant G:** *We want food. We kindly ask the government to give us food for free. Sometimes a person might not have money to buy food and we are encouraged to eat bananas, oranges, eggs, meat, fish and beans. Most of us do not have money to buy food; we just eat an unbalanced diet. We sometimes do not have cooking oil to put in the beans so we end up eating them boiled with salt only. I might have a vegetable garden. The least I can do is just cook them with water and salt only and would repeat it every day. I would like to ask the government to assist us with cooking oil, beans or maize so that we can eat nutritious food.*

**Participant H:** *We need food. If they can give us food it will be better. The Red Cross donors usually give us beans, cooking oil, etc. We are asking for donations in terms of food. Do you know that a woman will not have time to rest looking for means to survive? It is not proper to ask for food from other people's houses.*

**Participant I:** *It would be good if we can get food. We use to get the food from Red Cross but they have stopped. I do not know the reason. For the pills to work effectively, we need proper food and adequate medication.*

#### **Discussion of Sub-theme 5.4**

Rupiya (2006:160) states that “[m]alnutrition has a direct impact on the human body’s response to HIV/AIDS. Also some antibiotics, anti-tuberculosis (TB) drugs and antiretroviral drugs (ARVs) should be taken only in conjunction with adequate nutrition.” The quotes above indicate that food is a real need for HIV positive women. Most of the participants reported that they used to receive food parcels from Red Cross, but now the donors have pulled out. The participants asked for donors who can help them with food or that the government provide them with basic foodstuffs to survive. Pratt (2003:323) goes further stating that “[m]alnutrition is either directly or indirectly the cause of significant patient problem frequently encountered in HIV disease.” Many of the HIV positive women are starving; they struggle to put food on

the table. They are in need of food donations in order for them to survive and also to adhere to ARV treatment.

### **Sub-theme 5.5: Income generating projects**

**Participant D:** *We want projects like poultry farms so that we can support ourselves. We can sell chickens and get meat or eggs from the project. We are encouraged to eat eggs regularly.*

**Participant F:** *People want jobs. Many of us are widows and we need jobs to support our children. If you are not working, your children will not go to school and will be starving in the house, so having a job will help you to buy food for them and also send them to school. Even providing us with income generating projects will be good....*

**Participant H:** *To provide us with projects. The Action Firm people came and they wanted to start a gardening project with us. When they left, we used those gardens to grow our maize there. Projects like poultry farms are good so that we can provide for ourselves. You see some HIV positive women going to the brothels to sell their bodies so that they can get money to survive. Even if you give them food it is something temporary. We need something which lasts longer, like income generating projects.*

**Participant I:** *I wish we could be assisted with projects such as poultry farming so that we can have money to support ourselves. We need food as we have been told that our condition needs us to eat on time and regularly.*

### **Discussion of Sub-theme 5.5**

Income generating projects such as gardening and poultry were presented as a need for HIV positive women. As shown on the participants' profile, most of them are not working and they are struggling to make ends meet. The on-going economic crises in Africa have worsened the employment situation for women and men. However, women face even greater vulnerabilities in the labour market due to their relative lack of education and training (Ackerman & De Klerk, 2002:168). The participants indicated that there is a need for the provision of income generating projects so that they would be able to have an income and get food. Providing HIV positive women with income generating projects will enable them to be independent and also be in a position to support their families.

### 3.6 SUMMARY

The following themes and sub-themes came out of this research:

Theme 1 investigated the information that HIV positive women have regarding the disease. The sub-themes that emerged were understanding HIV and AIDS and the causes thereof, negotiation for safer sex and partners getting tested. Many HIV positive women have a good understanding of what HIV and AIDS are, as well as how HIV can be transmitted. It is still difficult for some HIV positive women to negotiate condom use in their relationships or marriages. Some of the men hid their HIV status from their wives.

Theme 2 looked at the information on ARV treatment. HIV positive women understood the importance of adherence to ARV treatment schedules. They understood that the purpose of the ARVs is to suppress or slow the progression of the virus and not to destroy it completely. Nausea, headaches, burning feet, stiff muscles, increased appetite and vomiting were some of the side effects of ARVs.

Theme 3 looked at the societal and HIV positive women's views on HIV and AIDS. Disclosure has been identified as a big mountain to climb once a person knows her status. Stigma and discrimination are still rife, although in some communities people have gained knowledge on the disease. People are beginning to change their attitude towards and perception of HIV positive women, although the changing process is slow. The distribution of ARV treatment was not connected to the political situation prevailing in the country. The traditional and faith healers misled the HIV infected women by attributing their sickness to witchcraft and angry ancestors, leading to non-adherence of ARV treatment.

Theme 4 focused on the experiences of being an HIV positive woman. It was evident from the HIV positive women that ARVs and cotrimoxazole drugs are given for free; they are only expected to buy medication for OIs. Lack of money had been highlighted as a major challenge for HIV positive women, because they need money to buy the prescribed medication, travel to the ARV treatment sites and meet their nutritional needs. The ARV treatment sites are far away from where the infected women stay and there are few of them. Participants also have to spend many hours in long queues before they receive treatment. A constant change in ARV drug types was noted and some of the drugs were in short supply. HIV positive women are referred

to big hospitals for diagnostic assessments and there are few viral load machines at the hospital, and sometimes they are out of order. Support is received from the family members, neighbours or support groups. There are few health care workers and they treat the patients with respect and dignity. Some of the health workers serving the HIV-infected people are also on ARV treatment.

The last theme, which is Theme 5, looked at the needs identified by HIV positive women. There is a need for adequate ARV treatment, by ensuring that the ARVs were available at the sites. There is a need to increase the ARV treatment sites and also the number of health care workers per site. Donors who could provide food to HIV positive women and sponsors to kick-start income generating projects are also needed.

The following chapter provides a summary, conclusion and recommendations regarding this study.

## CHAPTER 4

### SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

#### 4.1 INTRODUCTION

The summary of the research will be discussed in this chapter. The focus will be on how the aim and objectives of the study were met, as well as if the research question was answered. Conclusions emanating from this study will be made. These will be followed by recommendations for practice and for future research.

#### 4.2 SUMMARY

The objectives, goal and research question will be addressed, as well as how they were met.

##### 4.2.1 Objectives of the Study

The objectives of this study were as follows:

- ❖ To describe the phenomenon of HIV and AIDS in Southern Africa and specifically in Zimbabwe, the position of HIV positive women as a vulnerable group in society, and ARV treatment.
- ❖ To explore the challenges experienced by women with HIV and AIDS in Zimbabwe.
- ❖ To explore the challenges of HIV positive women in accessing and adhering to ARV treatment in Zimbabwe.
- ❖ To make recommendations for improving services in Zimbabwe.

Each objective will be discussed individually, as well as how it was achieved through the research study.

- **Objective One: To describe the phenomenon of HIV and AIDS in Southern Africa and specifically in Zimbabwe, the position of HIV positive women as a vulnerable group in society, and ARV treatment.**

This objective was achieved through the conducting of a literature study of HIV and AIDS and the challenges experienced by HIV positive women in accessing ARV treatment.

These factors were presented in Chapter 2 of the research report. The literature chapter explored the following factors: Zimbabwe's social, cultural, political and economic situation; HIV and AIDS prevalence and epidemiology in Southern Africa and Zimbabwe; antiretroviral treatment; and the challenges facing HIV positive women in accessing treatment.

- **Objective Two: To explore the challenges experienced by women with HIV and AIDS in Zimbabwe.**

This objective was achieved by means of the literature study and the empirical research. The literature study focused on women as a vulnerable group and the population most at risk. In many African societies, women are considered a second-class citizen and their ability to influence decisions about sexuality and accessing healthcare is very limited (Karim & Karim, 2010:515). The research data collected from the one-on-one semi-structured interviews revealed that disclosure, stigma and discrimination; traditional and faith healers' diagnosis of HIV and AIDS; side effects of ARVs; partners getting tested; and negotiation for safer sex contributed to the challenges faced by HIV positive women. Participants were given the opportunity to share their own experiences, feelings and perceptions.

- **Objective Three: To explore the challenges of HIV positive women in accessing and adhering to ARV treatment in Zimbabwe.**

This objective was achieved by means of the literature study and the empirical research. Literature states that due to the prevailing economic and political turmoil in Zimbabwe, there are many challenges experienced by HIV positive women in accessing ARV treatment, such as the shortage of healthcare workers, stigma and discrimination, nutritional factors, witchcraft and personal beliefs, logistics and technological issues, as well as poverty and economic factors. The data collected revealed that access to the medication for HIV-related OIs; the consultation fee and buying drugs for OI; good nutrition; availability of ARV treatment sites; access to ARVs and the time spent at the ARV sites; the availability and change of ARV regimens; adherence to treatment; referral for diagnostic assessments; and the availability and attitude of health care workers were factors impacting ARV treatment.

- **Objective Four: To make recommendations for improving services in Zimbabwe.**

This objective was addressed and achieved in this chapter. The recommendations are made later in this chapter. These recommendations are based on the research findings and conclusions drawn from the study, regarding the challenges experienced by HIV positive women in accessing ARV treatment.

#### **4.2.2 Goal of the Study**

The goal of the study was: **to explore the challenges experienced by HIV positive women with regard to accessing ARV treatment in Zimbabwe.** The achievement of this goal is discussed below.

The literature review chapter explored the following factors: the theoretical framework, Zimbabwe's current situation, HIV and AIDS prevalence and epidemiology in Southern Africa and Zimbabwe, antiretroviral treatment, and the challenges facing HIV positive women in accessing treatment. Under the theoretical framework, Health Behaviour Theory was used and the biopsychosocial model was applied. Biological, psychological, social and spiritual factors which influenced access to ARV treatment were explored.

Under the current situation in Zimbabwe, social, cultural, political and economic factors were elaborated on. HIV and AIDS trends and statistics were explored with regards to their prevalence and epidemiology in the continent. Under the challenges facing HIV positive women in accessing treatment, factors such as stigma and discrimination, gender inequality and cultural norms, location and environmental factors, poverty and economic factors, nutrition, shortage of health care workers and logistics, and technological issues were discussed.

The empirical research yielded the following themes: information regarding HIV and AIDS, information on ARV treatment, societal and HIV positive women's views on HIV and AIDS, experiences of being an HIV positive woman, and needs identified by HIV positive women. Each of these themes had sub-themes which helped to provide more detailed information on the challenges experienced by HIV positive women in Zimbabwe in accessing treatment. Information regarding HIV and AIDS had the following sub-themes: understanding HIV and AIDS and the causes thereof, negotiation for safer sex, and partners getting tested. Theme 2, information on ARV treatment, had sub-themes related to the importance of adherence to

treatment schedules, purpose of ARVs and the side effects of ARVs. Societal and HIV positive women's views on HIV and AIDS covered sub-themes such as disclosure, stigma and discrimination, ARV treatment and politics, and traditional and faith healers' diagnosis of HIV and AIDS.

Experiences of being an HIV positive woman are related to access to medication for HIV-related OIs, consultation fees and buying drugs for OIs, good nutrition, and access to clean water. The availability of ARV treatment sites and proximity to these sites were also challenges. Accessing the ARV sites and the time spent at the ARV treatment sites were hindrances to adherence. The availability of ARV regimen, change of ARV regimen, and referral for diagnostic assessments are some of the sub-themes identified. Support from the family and community, availability of health care workers, and the attitude of health care workers were addressed. The needs identified by HIV positive women were adequate antiretroviral treatment, sufficient ARV sites nearby, adequate treatment from health care workers, food, and income generating projects.

#### **4.2.3 Research Question**

The research question was:

**What are the challenges experienced by HIV positive women with regard to antiretroviral treatment in Zimbabwe?**

The data collected from the one-on-one interviews revealed themes and sub-themes, relating to the challenges experienced by HIV positive women in accessing ARV treatment. As the research was qualitative in nature, descriptive data was obtained. These descriptive experiences of HIV positive women were presented in the previous chapter on research findings. The following themes reflect the challenges experienced by HIV positive women with regard to ARV treatment in Zimbabwe.

- Theme 1: Information regarding HIV and AIDS
- Theme 2: Information on ARV treatment
- Theme 3: Societal and HIV positive women's views on HIV and AIDS
- Theme 4: Experiences of being an HIV positive woman
- Theme 5: Needs identified by HIV positive women

These themes were discussed in-depth, together with their sub-themes in the previous chapter.

**Table 4: Table of themes and sub-themes**

<p><b>Theme 1:</b> Information regarding HIV and AIDS</p>	<p><b>Sub-themes:</b></p> <ul style="list-style-type: none"> <li>➤ Understanding HIV and AIDS the causes thereof</li> <li>➤ Negotiation for safer sex</li> <li>➤ Partners getting tested</li> </ul>
<p><b>Theme 2:</b> Information on ARV treatment</p>	<p><b>Sub-themes:</b></p> <ul style="list-style-type: none"> <li>➤ Importance of adherence to ARV treatment schedules</li> <li>➤ Purpose of ARVs</li> <li>➤ Side effects of ARVs</li> </ul>
<p><b>Theme 3:</b> Societal and HIV positive women's views on HIV and AIDS</p>	<p><b>Sub-themes:</b></p> <ul style="list-style-type: none"> <li>➤ Disclosure</li> <li>➤ Stigma and discrimination</li> <li>➤ ARV treatment and politics</li> <li>➤ Traditional and faith healers' diagnosis of HIV and AIDS</li> </ul>
<p><b>Theme 4:</b> Experiences of being an HIV positive woman</p>	<p><b>Sub-themes:</b></p> <ul style="list-style-type: none"> <li>➤ Access to medication for HIV-related OIs</li> <li>➤ Consultation fee and buying drugs for OIs</li> <li>➤ Good nutrition and access to clean water</li> <li>➤ Availability of ARV treatment sites and the proximity to these sites</li> <li>➤ Accessing the ARV treatment sites</li> <li>➤ Time spent at the ARV treatment site</li> <li>➤ The availability of ARV regimen</li> <li>➤ Change of ARV regimen</li> </ul>

	<ul style="list-style-type: none"> <li>➤ Referral for diagnostic assessments</li> <li>➤ Support from the family and community</li> <li>➤ Availability of health care workers</li> <li>➤ Attitude of health care workers</li> </ul>
<p><b>Theme 5:</b> Needs identified by HIV positive women</p>	<p><b>Sub-themes:</b></p> <ul style="list-style-type: none"> <li>➤ Adequate antiretroviral treatment</li> <li>➤ Sufficient ARV sites nearby</li> <li>➤ Adequate treatment from health care workers</li> <li>➤ Food</li> <li>➤ Income generating projects</li> </ul>

## 4.3 CONCLUSIONS

### 4.3.1 Conclusions regarding the literature study

The conclusions were drawn from the related literature study in Chapter 2 and the empirical data presented in Chapter 3. The Health Behaviour Theory proved to be appropriate for the study. It helped to identify the challenges experienced by the participants in accessing ARV treatment. The use of a biopsychosocial model worked effectively for this study as it took a holistic approach to ARV treatment access. All factors which hindered the participants' access to treatment were taken into consideration and addressed.

### 4.3.2 Conclusions regarding the research methods

The researcher is of the opinion that the findings of this study cannot be generalised but could be transferrable to a similar setting in Zimbabwe with a similar population. Analysis was done according to the qualitative approach and data analysis process. The qualitative approach, using collective case studies and one-on-one semi-structured interviews, proved to be appropriate for this study. The information gathered was in the form of words and descriptions to give meaning to the challenges experienced by these HIV positive women in accessing ARV treatment in Zimbabwe.

The use of the semi-structured interview schedule (Appendix 4) enabled the researcher to obtain first-hand information from the participants, as it allowed freedom to explore certain topics further. It can therefore be concluded that the semi-structured interview schedule worked effectively as a method of data collection used in interviewing to answer the research question. The researcher can therefore recommend these methods to future researchers who are planning to explore the challenges of HIV positive women. The collective case study design was appropriate as the researcher was able to broaden her understanding of the challenges experienced by the participants, by exploring the challenges and experiences of different women (case studies). These findings from the collective cases were presented according to the common themes and sub-themes identified.

### **4.3.3 Conclusions regarding the thematic analysis of the research findings**

The following conclusions are based on the key findings of this study, as discussed per theme in chapter 3.

#### **4.3.3.1 Theme 1: Information Regarding HIV and AIDS**

It is vital for HIV positive women to have information on what HIV and AIDS is and the causes thereof. It is the researcher's opinion that having knowledge about the disease can contribute to the understanding of the importance of accessing and adhering to the ARV treatment. From the research findings it was noted that the participants expressed that they have adequate information on HIV and AIDS. The access to HIV and AIDS information is not limited to HIV positive women only; there is free access of information to all.

##### ***Sub-theme 1.1: Understanding HIV and AIDS and the causes thereof***

Analysis of data has shown that most of the participants have a clear understanding of HIV and AIDS and the causes thereof. Understanding of the disease and its causes can help ensure adherence to ARV treatment. It is the opinion of the researcher that having a good knowledge of the causes of HIV and AIDS will help them to practise safer sex and will enable them to share information with others, as well as support one another.

##### ***Sub-theme 1.2: Negotiation for safer sex***

Although negotiation for safer sex amongst HIV positive people is preached everywhere, it seems the concept is difficult to implement with many African men. Participants were faced with the challenge of negotiating for condom use in their marriages or relationships. Failure to practise safe sex leads to re-infections with other HIV strains.

### ***Sub-theme 1.3: Partners getting tested***

It is crucial for partners to get tested so that they will know their status and support one another. It emerged from the research findings that most men were not willing to get tested or to disclose their status to their partners. Most of the participants did not know the status of their partners and these men were refusing to use condoms.

### **4.3.3.2 Theme 2: Information on ARV treatment**

HIV positive women need to be provided with adequate information on ARVs and how to take them. From the research findings, it was noted that most the participants had knowledge on ARV treatment and how it works. The researcher argues that if the participants are well-informed about their medication, how to take it and its importance, they are more likely to be committed and adhere to their treatment.

#### ***Sub-theme 2.1: Importance of adherence to ARV treatment schedules***

ARV treatment is a life-long treatment; once one has started it, one should never stop the treatment. Participants in this study showed a good understanding of the importance of adherence to treatment schedules. It is the researcher's opinion that this gives them the ability to be in control of their illness and they understand the consequences of not adhering to the treatment.

#### ***Sub-theme 2.2: Purpose of ARVs***

This sub-theme links in well with the previous one of the importance of adherence to treatment schedules. For one to be able to be adherent and stick to the time table of taking the drugs, one has to be educated on the importance and the purpose of ARVs. The results indicated that most participants had a good understanding of why they were taking the ARVs. It is the researcher's opinion that participants are motivated to adhere to their treatment if the treatment yields positive results.

#### ***Sub-theme 2.3: Side effects of ARVs***

Participants experienced a myriad of side effects of ARVs ranging from headaches, lack of energy, cramps and prickling sensation on the feet and hands. It emerged from study findings that even if they went back to the health care workers to complain, they were not given any medication. The researcher argues that the side effects of ARVs contribute to poor adherence to treatment as some of the side effects are unbearable.

#### **4.3.3.3 Theme 3: Societal and HIV positive women's views on HIV and AIDS**

It emerged in the study findings that different societies have different views regarding HIV and AIDS. It surfaced in the study that some participants were of the opinion that their communities have a better understanding of the disease and they accept HIV positive people into their society. There are still other people who regard HIV and AIDS as a curse and they treat HIV-infected people unfairly, isolating them from society. The biopsychosocial model makes provision for the community environment having a greater influence on the person's health and they are the people who can motivate someone to change their habits (Sarafino, 2006:14). All in all it is the researcher's opinion that adherence and access to ARV treatment is greatly influenced by the society's views of HIV positive women.

##### ***Sub-theme 3.1: Disclosure***

Most of the participants found it difficult to disclose their status to their families and community at large. It took them a long time to disclose their HIV status. No man lives in an island; you need support from other people in order to function well. It emerged in the study findings that some of the participants who disclosed their status received support from their families and society and were accepted into the community. However, some were neglected, rejected and deserted by their partners and were accused of being promiscuous. Disclosure brought about life changes in the lives of HIV positive women.

##### ***Sub-theme 3.2: Stigma and discrimination***

Stigma and discrimination is still prevalent in some communities, depending on the people's level of understanding of HIV and AIDS. The negative attitude of some communities became apparent when some participants felt that they were being looked down upon and were not respected in the community because of their HIV status and this thwarted their confidence and self-esteem. It is the researcher's opinion that participants had to suffer a double tragedy; they have to cope with the physical changes and side effects of ARVs, as well as society's negative views and perceptions of them. There are some societies which are enlightened and they tend to treat HIV positive people with respect and dignity. Stigma and discrimination make access to treatment very challenging.

### ***Sub-theme 3.3: ARV treatment and politics***

Politics has a major role to play in determining the future of the country. The researcher found that participants reported that ARV treatment was not affected by the political situation in the country. It emerged that there was no link between politics and the ARV roll out in the country.

### ***Sub-theme 3.4: Traditional and Faith healers' diagnosis of HIV and AIDS***

Traditional and faith healers have a major role to play in influencing HIV positive women to adhere to their treatment. Many African women consult with traditional and faith healers about their problems, be they medical or social. It emerged from the study that some participants were not convinced that taking ARVs on their own would help improve their condition. They would use the traditional and western medicines concurrently and some HIV infected women would stop taking their ARV treatment, thereby putting their lives at risk.

#### **4.3.3.4 Theme 4: Experiences of being an HIV positive woman**

The participants experienced a wide range of challenges. They need to have access to medication for HIV-related opportunistic infections and they also need money to buy such medication. The ARV sites are few and located very far from the participants. The participants had to wait for long hours in queues before they were served and their ARV regimen was changing constantly. Most participants received adequate support from their families and community. The findings indicated that health care workers were reported to be few with poor services. The theme of the experience of being an HIV positive woman is a very significant theme, because it elicits comprehensively all the challenges the participants encountered with regard to accessing ARV treatment.

### ***Sub-theme 4.1: Access to medication for HIV-related OIs***

The participants were mainly concerned about the availability of medication for other diseases. Opportunistic infections (OIs) present themselves at different stages of the disease. The researcher found that access to medication for OIs is very limited. ARVs and cotrimoxazole drugs were given the first preference in the management of HIV and AIDS, thereby overlooking the need to have other drugs in the management of OIs.

### ***Sub-theme 4.2: Consultation fee and buying drugs for OIs***

This sub-theme links with the one above regarding access to medication for HIV-related opportunistic infections. Participants were expected to buy their own medication for OIs. The

shortage of money came out prominently as a challenge, as most participants were not formally employed.

***Sub-theme 4.3: Good nutrition and access to clean water***

HIV positive women are expected to eat a balanced diet and also drink clean water. This seems to be impossible in Zimbabwe where poverty is reigning its terror. Most participants were unemployed; they did menial jobs to survive. Participants found it difficult to get money to buy basic food, let alone enough for a balanced diet. They were surviving on the little they could afford. The findings also indicated that the drinking water was clean in some areas. Those who used running tap water experienced erratic water cuts. It emerged from the study's findings that it was very difficult for participants to take their treatment without adequate food and some of the drugs also increase appetite. Shortage of adequate food would compromise the health of participants. This would also have a major impact on their access to ARV treatment.

***Sub-theme 4.4: Availability of ARV treatment sites and the proximity to these sites***

ARV treatment sites should be available and accessible to everyone. The results of the study indicated that participants had mixed feelings regarding the availability of ARV treatment sites and their proximity. Some indicated that the treatment sites were enough and were close to them. Those were the responses of the participants who were mainly in urban areas. In rural areas HIV positive women had to travel long distances to access ARV treatment. The distance they travelled had a major impact on their adherence and access to treatment. The closer the ARV sites, the more the participants were likely to adhere to treatment. On the other hand, fear of stigma and discrimination compelled some participants to travel to the sites which were far away from them.

***Sub-theme 4.5: Accessing the ARV treatment site***

The way HIV positive women access ARV treatment sites affected adherence to ARV treatment. Participants had to access the ARV treatment sites through various means. Some had to walk long distances and they would have to leave the house very early in the morning. Those who used transport to get to the treatment sites experienced money shortages. Participants had to walk long and tiresome distances or borrow money in order to meet their appointment dates.

#### ***Sub-theme 4.6: Time spent at the ARV site***

When people visit the health care centres, they expect good service delivery and not to spend the whole day in queues. The dissatisfaction of participants became apparent when they stated that they experienced very long queues at the ARV treatment sites. The results also showed that the health care workers were very slow in delivering services to the patients. It is the researcher's opinion that some HIV positive women might have avoided going to collect their treatment for fear of having to wait in the queues for long, gruesome hours. The service delivery system at some ARV treatment sites have been reported to be very poor.

#### ***Sub-theme 4.7: The availability of ARV regimen***

ARVs are lifesaving drugs and they should be readily available to HIV positive women. The success or failure of treatment is totally dependent on the availability of and adherence to the drugs. HIV positive women experience a shortage of ARV drugs and also drug theft. Participants were mainly concerned about the availability of ARVs due to stock-outs experienced at some ARV treatment sites. As a result they were panicking, thinking that they were going to die.

#### ***Sub-theme 4.8: Change of ARV regimen***

The findings indicated that participants reported that their ARV regimen was changed constantly. The participants were not sure of the reason for the change of their ARV regimens. All the participants indicated that they were not happy with the way their treatment kept on changing. It also caused confusion amongst some participants. In order for HIV positive women to adhere to ARV treatment a clear explanation should be given on why they should take the ARVs or why they should change their regimen.

#### ***Sub-theme 4.9: Referral for diagnostic assessments***

It is vital for HIV positive women to check their CD4 count regularly so that they will be given the correct treatment. It surfaced in the study that participants were usually referred for diagnostic assessments after six months. It has been found that viral load assessment machines were few at the hospitals and would often break down. There is another private company, New Start centre, which can also charge \$1 for a diagnostic assessment. Lack of money, machinery break down and long queues were the major factors which forced participants to go for several months or years without going for diagnostic assessment and this affected the success of the treatment.

#### ***Sub-theme 4.10: Support from the family and community***

Human beings need support from other people to function well; you cannot survive on your own. The researcher found that participants received support from their families and community. The responses were very individual in nature, with some participants receiving good support from their families and support groups. All participants indicated that they received support from their family members. What did seem to transpire is that the support needed by most HIV positive women was the material and financial support which they did not get from communities. Those who were involved in support groups seemed to cope much better.

#### ***Sub-theme 4.11: Availability of health care workers***

The ever increasing number of people needing ARVs puts a strain on the health care workers available. Health care workers have to cope with absenteeism, brain drain, poor working conditions and remunerations. It emerged from the study findings that participants reported that the services they received at the ARV sites were poor.

#### ***Sub-theme 4.12: Attitude of health care workers***

If patients are treated well at the ARV treatment sites, they are more likely to adhere to their treatment and would not hesitate to visit the ARV treatment sites regularly. The results of the study indicated that most of the participants had no complaints with regard to the health care workers' attitude. However, there were some health care workers who were reported to be very rude, insensitive and uncaring, especially the junior staff.

### **4.3.3.5 Theme 5: Needs identified by HIV positive women**

Participants felt that there were some things which needed to be improved in order to increase their access to ARV treatment. They indicated their own needs which have to be addressed. Meeting of the stated needs would help to ameliorate the challenges they experienced with regards to adherence and accessing ARV treatment. Participants felt that there was a great need for them to be provided with adequate ARV treatment, sufficient ARV sites, food and projects which would bring income.

#### ***Sub-theme 5.1: Adequate antiretroviral treatment***

It emerged from the research findings that the information on HIV and AIDS and treatment given to participants were adequate. Participants highlighted that there was a need to have the

ARV stock available at all sites. This would save them the time and money needed to travel to district or provincial hospitals to look for the ARV drugs prescribed to them. They would also be able to access treatment anytime they run short of drugs.

#### ***Sub-theme 5.2: Sufficient ARV sites nearby***

Walking for long distances to access ARV treatment is a major concern for many participants. The study findings indicated that there was a need to increase ARV sites, bringing them closer to the people. Increasing ARV sites and bringing them closer to the people will help to reduce the burden of looking for transport money or walking for long distances. It will also help to ensure that everyone has access to treatment.

#### ***Sub-theme 5.3: Adequate treatment from health care workers***

Participants expected the health care workers to act as professionals at all times and be sensitive and understanding towards them. They indicated that they wanted fast service when they went for their treatment, hence there is need to increase the number of health care workers at the treatment sites. A need to educate health care workers on how to handle HIV positive people has been indicated. Participants wanted to be treated with respect and dignity for them to feel human.

#### ***Sub-theme 5.4: Food***

Food has been highlighted as the real need for HIV positive women. Participants felt that ARVs could not work effectively without eating a balanced diet. It is the opinion of the researcher that lack of good nutrition has a major impact on access to ARV treatment. For ARV treatment to work effectively, it has to be accompanied with good food and peace of mind.

#### ***Sub-theme 5.5: Income generating projects***

The existing patriarchal society in Zimbabwe has made women dependent on and loyal to their husbands or partners. They occupy low positions in society. It surfaced in the study findings that many participants were unemployed and were struggling to survive. They felt that income generating projects such as gardening and poultry farming were a need for them. This would enable them to get food and have an income at the same time. The projects will also enable them to be independent and become active rather than living a sedentary lifestyle.

## 4.4 RECOMMENDATIONS

It was in the context of the conclusions discussed above that recommendations, to address the challenges experienced by HIV positive women in accessing ARV treatment were made. The recommendations are made per theme.

### 4.4.1 Recommendations–Theme 1: Information regarding HIV and AIDS

#### *Sub-theme 1.1: Understanding HIV and AIDS and the causes thereof*

To improve adherence and access to ARV treatment, education as part of understanding HIV and AIDS and the causes thereof remains crucial. The researcher believes that the dissemination of HIV and AIDS information should be an on-going process and not a one-time event. During the testing and treatment period, people need to be reminded constantly about the disease, its causes and the importance of practising safe sex.

#### *Sub-theme 1.2: Negotiation for safer sex*

The researcher believes that strategies should be put in place on how HIV positive women can negotiate for safe sex with their partners. It is very difficult for women to insist on condom use in their relationships, due to fear of violence and also cultural norms which oppress women. HIV positive women's concerns regarding negotiation for safer sex can be addressed by meeting two major objectives. The first objective will be to create positive attitudes by enlightening both HIV positive men and women on the pedagogic benefits of practising safe sex, particularly in avoiding re-infections. The second objective should be to make female condoms readily available.

#### *Sub-theme 1.3: Partners getting tested*

Men tend to hide their status from their partners and some are also reluctant to get tested. It is recommended that awareness campaigns be held focusing on men getting tested and sharing their status with their partners. If men are enlightened on the importance of getting tested, they become open to their partners about their status. They will be able to support, encourage and remind each other to take their treatment.

#### **4.4.2 Recommendations–Theme 2: Information on ARV treatment**

##### ***Sub-theme 2.1: Importance of adherence to ARV treatment schedules***

There is a need to keep on reminding and encouraging HIV positive women to take their ARVs regularly without skipping any. It is recommended that HIV infected women be educated about the importance of adherence and keeping their time of taking ARVs.

##### ***Sub-theme 2.2: Purpose of ARVs***

Information should be accessible for all and should be readily available to HIV positive women. Knowledge is power; the more people are well-informed about the purpose of taking ARVs, the more they are likely to adhere to treatment.

##### ***Sub-theme 2.3: Side effects of ARVs***

ARVs are lifelong drugs and commitment is needed once you start taking them. There are many side effects associated with taking ARVs. It is therefore recommended that before starting ART, HIV positive women should be prepared for the possible side effects of the treatment. They should be informed that the side effects of ARVs can last for a long time, depending on the individual's immune system. This will help HIV positive women from being worried and uncertain if they will ever feel better. When you have concerns and worries, you need reassurance from other people that all will be well. The same goes for HIV positive women when they visit the nearest HIV treatment sites presenting their problems, which are most likely the side effects of ARVs. The health care workers should be empathic and give them hope that their problems will come to an end.

#### **4.4.3 Recommendations–Theme 3: Societal and HIV positive women's views on HIV and AIDS**

##### ***Sub-theme 3.1: Disclosure***

Disclosure seems to still be a high mountain to climb for many HIV positive people. During the awareness campaigns and post-counselling sessions, it is recommended that the focus should be on encouraging disclosure. A problem shared is half solved; through disclosure HIV positive women can get emotional, psychological and physical support to help them deal with the disease. The researcher believes that sharing one's status with the family or a friend will help to release the burden one is carrying on one's shoulders. It is also recommended that the strategy of a buddy system be strengthened in order to ensure adherence and access to ARV treatment. Those who feel uncomfortable to disclose their status to their families should be

encouraged to approach some professionals like social workers with their concerns or problems for counselling and emotional support.

### ***Sub-theme 3.2: Stigma and discrimination***

Stigma and discrimination thwart the efforts to ensure access to ARV treatment for HIV positive women. It is highly recommended that communities should be educated about HIV and AIDS. The education should focus on tolerance and acceptance of HIV positive people in society. There is a need to mitigate stigma and discrimination at all levels. HIV positive people need to live a normal life like anyone else. There is a need to revive their confidence and self-esteem and this can be achieved by support groups and one-on-one counselling. People should be encouraged to treat HIV positive women with respect and dignity and they should be encouraged to take part in community activities.

### ***Sub-theme 3.3: ARV treatment and politics***

To ensure access to ARV treatment, it is prudent that during political campaigns and rallies, politicians should encourage people to get tested and take their medication. HIV/AIDS is a reality and is killing many people on a daily basis; it was declared a national disaster. Politicians should join hands with other stakeholders in the fight against HIV and AIDS and ART roll out to make sure that there is adequate supply and access to ARV treatment.

### ***Sub-theme 3.4: Traditional and faith healers' diagnosis of HIV and AIDS***

Traditional healers and faith healers are misleading people, making them discontinue their treatment. Since traditional and faith healers are consulted by many HIV positive people, they should be informed about the pedagogical benefits of taking ARVs for HIV positive people. It would be important therefore to include them in the conscientisation exercise which should be deliberately conducted as an advocacy measure meant to increase access to ARV treatment for HIV positive women. Dissemination of knowledge on the importance of adhering to ARV treatment could be done by traditional and faith healers who happen to be approached by HIV positive women. It is recommended that extensive education be provided to traditional and faith healers about the disease. In order to allow traditional and faith healers to feel involved in the effort to increase access to ARV treatment policy-makers should seek ideas from them as policy implementers, as a way of making faith healers appreciate the importance of adherence to ARV treatment. They should be involved in the drafting of HIV and AIDS policies and be part of all the programmes on HIV and AIDS so that they will not crush treatment efforts

with their doctrines. HIV positive women should also be encouraged to take their medication regularly and stop relying on traditional medicines for healing, since there is no cure for the disease.

#### **4.4.4 Recommendations–Theme 4: Experiences of being an HIV positive woman**

##### ***Sub-theme 4.1: Access to medication for HIV-related OIs***

The health care system of Zimbabwe has deteriorated. As HIV and AIDS present with various opportunistic illnesses, medication for all illnesses should be made available to all. The Ministry of Health and Child Welfare have to make an effort to ensure that all the ARV sites have enough stocks of medication for all the diseases. Primary health care and ARV treatment should run concurrently.

##### ***Sub-theme 4.2: Consultation fee and buying drugs for OIs***

Living as an HIV positive woman in Zimbabwe is not easy. There is no access to medication for HIV-related OIs. In light of the conclusion drawn above that HIV positive people were expected to pay a consultation fee and buy medication for OIs, it is recommended that effort has to be made by the government of Zimbabwe to devote serious attention to ART policy and make sure that primary health care is addressed at the grassroots level. There is a need to ensure that medication for all the diseases, be they minor or major, is readily available to all. An effort should also be made to improve the health delivery system at ARV treatment sites, whereby HIV positive women would feel comfortable to visit knowing that they will get help.

##### ***Sub-theme 4.3: Good nutrition and access to clean water***

HIV positive people are expected to eat a balanced diet, therefore it is recommended to provide HIV positive women with food parcels and teach them how to make their drinking water safe. As the country's economic condition is not strong and providing HIV positive women with food parcels may be an expensive endeavour, the government could source donor funding from international Non-Governmental Organizations such as USAID, Care International, Red Cross and United Nations which previously provided food and projects to the poor. The researcher believes that it is very difficult to take ARV treatment on an empty stomach. Effort should be made to work together with local churches and local Non-Profit Organizations to provide material assistance to HIV positive women who are struggling to make ends meet. Also there is need to educate HIV positive people on the importance of hygiene, especially about drinking

clean water and methods to purify their drinking water. This will help to avoid an out-break of water-borne diseases, thereby ensuring the effectiveness of ARV treatment.

***Sub-theme 4.4: Availability of ARV treatment sites and the proximity to these sites***

The ARV treatment sites are often very far away and usually the sites are congested with people who have come for their ARV supply. It is recommended that the number of ARV sites be increased and also brought closer to the people. Then people will not have to travel long distances or borrow transport money. Bringing the ARV sites closer to the people will help to increase access to ARV treatment since HIV infected women will no longer have to travel long distances. Increasing ARV sites will also help to curb overcrowding at the ARV sites and improve service delivery. Mobile ARV units are also recommended.

***Sub-theme 4.5: Accessing the ARV treatment sites***

This recommendation links with the one above regarding bringing ARV treatment sites closer to the people. Effort should be made to improve ART roll-out by increasing the number of ARV treatment sites in the country. It is also recommended that the ART outreach programmes be expanded to cover many inaccessible areas. This can be achieved by increasing the number of health care workers serving different areas, especially in rural areas. This will relieve HIV positive women from walking long distances or borrowing transport money to get to the ARV treatment sites. Mobile ARV units are encouraged.

***Sub-theme 4.6: Time spent at the ARV treatment site***

Debriefing sessions and regular staff meetings should be conducted with the health care workers so that they will have the ample opportunity to vent their frustrations. The management should also recognise the hard work of health care workers and praise them so that they can feel motivated to do their work. Socializing of health care workers during working hours shows that they lack motivation and enthusiasm to do their job. It is recommended that their remunerations be reviewed and their numbers at the ARV sites be increased, so as to ensure effective and efficient service delivery. HIV positive women should also be informed beforehand to expect some delays in getting their treatment if the staff is short on that particular day. This will prevent patients from losing confidence and trust in the health care system. HIV positive women should be taught and encouraged to be patient when visiting the ARV treatment sites, bearing in mind that there is a shortage of health care workers at some ARV sites and also that the number of people who need ARVs is increasing daily.

#### ***Sub-theme 4.7: The availability of ARV regimen***

Once you have started taking ARV drugs, you will have to take them for the rest of your life. Missing out on some drugs will compromise your health. It is therefore recommended that all stocks of ARV regimens should be readily available at ARV treatment sites. Effort should be made to ensure that ARV manufacturing companies produce enough ARV drugs to cover all sites. Stock-taking exercise should also be implemented at ARV treatment sites in order to curb drug theft and stock-outs. When the stock-out was experienced, some HIV positive women panicked thinking that they were going to die. It is recommended that the health care workers should reassure HIV infected women that they will get their treatment. There is need for on-going counselling for HIV positive women, especially when stock-outs are encountered. People should also be advised to come back anytime if their medication is missing. The health care workers should not refuse to give ARVs to HIV positive women who come complaining about missing pills in their boxes. It is also recommended that on issuing out the ARV treatment, the health care workers should count the pills together with the patients to ensure that they get enough pills and this will help to curb the problem of medication theft.

#### ***Sub-theme 4.8: Change of ARV regimen***

Access to ARV treatment will improve if the drugs are supplied to ARV treatment sites regularly without waiting for the site to go out of ARV stock. ARV regimen should not be changed without HIV positive women's knowledge. It is recommended that health care workers discuss the patients' conditions with them and also prepare them for the change of ARV regimen. There is also a need to explain the reason for changing the ARV regimen rather than leaving HIV positive women with speculations. The researcher believes that explaining to HIV infected women the reason for changing their ARV drugs would help to avoid fear and confusion. Health care workers should also have the patience to explain how the new ARV regimen should be taken. If possible the Ministry of Health and Child Welfare should use only a few pharmaceutical companies to manufacture ARVs and such companies should endeavour to keep these drugs similar in terms of drug quantity, size and colour. This will help to mitigate the confusion and fear associated with the constant change of ARV regimen amongst HIV positive women.

#### ***Sub-theme 4.9: Referral for diagnostic assessment***

Many participants took a long time before they went for diagnostic assessments due to machine break-down and also long queues. It is therefore recommended that the hospitals should

purchase more machines for viral load detection. This will help to hasten the process of diagnostic assessments. It will be prudent to have viral load detection machine(s) at each and every ARV site so that HIV positive women will not have to travel long distances to district and provincial hospitals for diagnostic assessment. If there are many machines, people are more likely to go for diagnostic assessment regularly since they will not have to wait in long queues and they will get their results quickly. If the government cannot purchase more viral load detection machines, it is recommended that the ones available should be serviced regularly to improve service delivery. This will avoid a situation whereby the machines break down and HIV positive people are sent home without being assisted and asked to come back when the machines are fixed. Dissemination of information on the importance of checking one's CD4 count regularly should be done in order to ensure that the correct ARV regimen is taken. This will also encourage HIV positive women to improve their lifestyles if they keep checking and are aware of their CD4 count.

***Sub-theme 4.10: Support from the family and community***

HIV positive women need support from their families, loved ones and communities in order to cope with the disease. For those who cannot get support from their families, it is recommended for them to join the support groups for HIV positive women. Some HIV positive women in this study reported that they did not have people to support them. It is therefore recommended that the strategy of the buddy system be taught and strengthened at all levels whereby a parent, brother, sister, relative or a friend can act as a support structure to an HIV positive woman. This will help to ensure adherence and access to ARV treatment. Referral to social workers for interventions is also recommended, because most of the HIV positive women seem not to know the existence of the social workers in the area. The social workers should be visible in all areas and advertise their services to the community.

***Sub-theme 4.11: Availability of health care workers***

It has been reported that there was a shortage of health care workers at the ARV treatment sites and this will lead to a burnout of the available health care workers. Staff burnout can be avoided by hiring and placing sufficient health care workers at different ARV treatment sites. It is also recommended that health care workers be provided with compassionate fatigue workshops in order to avoid burnout and to lighten the burden of having to deal with the ever increasing number of HIV people needing ARVs. Improving the working conditions and remunerations of health care workers in the public sector will go a long way in retaining the existing staff and

also attracting new staff. Giving the staff incentives, promotions and appraisals will help to keep the staff and motivate them to work hard, knowing that their efforts will be noticed and awarded. This will help to ensure effective and efficient service delivery to HIV positive women, thereby fostering adherence to ARV treatment.

#### ***Sub-theme 4.12: Attitude of health care workers***

Health care workers are expected to act professionally and adhere to the code of conduct since they deal with different people on a daily basis. Improving the attitude of junior staff can be done through government sponsored staff development workshops and professional development programmes for health care workers at community, district and provincial levels. The focus should be to make them aware of their attitude towards HIV positive patients and to equip them with the requisite skills to implement when dealing with HIV positive women. This will help the staff to be sensitive and compassionate towards HIV positive women and will improve their access to ARV treatment. The provision of short course programmes for health care workers focusing on how to handle HIV positive people would be beneficial. Health care workers should be taught continuously on how to handle difficult patients. Suggestion boxes can be placed at each ARV site where HIV positive women can drop their comments and complaints. This will help to improve service delivery and ensure constant access to ARV treatment.

### **4.4.5 Recommendations–Theme 5: Needs identified by HIV positive women**

#### ***Sub-theme 5.1: Adequate antiretroviral treatment***

Since there are many people in need of ARVs, it would be prudent to have an adequate ARV treatment supply. As it has already been discussed on sub-theme 4.7 regarding the availability of ARV regimen, it is recommended that all ARV regimens be available at all ARV treatment sites. This will help to reduce stock-outs and will also ensure access to ARV treatment for HIV positive women. Regular checks and stock taking of ARVs should be conducted on treatment sites to ensure that there is adequate ARVs for HIV-infected people.

#### ***Sub-theme 5.2: Sufficient ARV sites nearby***

This sub-theme links in with sub-theme 4.5 regarding accessing the ARV treatment sites. It is recommended the number of ARV treatment sites be increased, especially in the rural areas where HIV positive women travel long distances to get to the ARV sites. This will help ensure

adherence, as many HIV positive women can access the sites on foot. This will also cut travelling costs and long hours spent in the queue before receiving treatment.

***Sub-theme 5.3: Adequate treatment from health care workers***

To avoid repetition, the recommendations for this sub-theme have already been discussed on sub-theme 4.12 regarding the attitude of health care workers.

***Sub-theme 5.4: Food***

There is shortage of food in Zimbabwe due to erratic rains and also the high rate of poverty and unemployment. This sub-theme links with sub-theme 4.3 regarding good nutrition and access to clean water and the recommendations provided thereof.

***Sub-theme 5.5: Income generating projects***

HIV positive women should be taught to be entrepreneurs and encouraged to be self-sufficient. It would be prudent for the government to provide income generating projects or to look for donors who are willing to launch small projects targeting HIV positive women. This will help to foster financial independence. These projects should be sustainable in order to ensure that HIV positive women have enough food on their tables and will go a long way in ensuring access to ARV treatment. HIV positive women should also be equipped with small business skills and entrepreneurial skills so that they can maintain sustainable projects in order to be able to support themselves and their children. This will enable them to get food and an income from their proceeds at the same time.

It can be concluded that although some of the recommendations given may not sound new, they however remain relevant considering that HIV positive women experience challenges in accessing ARV treatment despite the policies implemented focusing on ARV roll-out in the country. There may not be a simple and immediate solution to address the challenges experienced by HIV infected women in accessing ARV treatment, but there is however a need to explore every avenue to create opportunities to improve access to ARV treatment for HIV positive women. The good news is that in literature there is a growing body of knowledge that highlights the challenges experienced by HIV positive women in societies, raising the question of when these challenges are going to be addressed. While ARVs are considered to be lifesaving drugs, participants in this study still experienced challenges in adhering to and accessing the ARV treatment.

#### **4.4.6 Recommendation for Future Research**

Future research should be done on HIV positive women from different cultural and ethnic groups, different age groups and urban versus rural areas to see if the experiences and challenges are similar. A bigger national quantitative study would be beneficial. Another recommendation is a qualitative study exploring the experiences of health care workers at ARV sites, aiming to understand their challenges as well and finding ways to improve service delivery to HIV positive people in the country. Similar studies with men should also be considered.

#### **4.4.7 The Way Forward**

HIV positive women experience a wide range of challenges in accessing ARV treatment. There is a need to educate the public on HIV and AIDS, so as to eradicate stigma and discrimination in many communities. Traditional and faith healers should form part of the team which helps to fight against HIV and AIDS. They need to receive formal education first regarding the disease. To increase access to treatment, there is a need to increase treatment sites and also to bring them closer to the people. Medication for HIV-related opportunistic infections should be available to HIV positive women for free. Health care workers should explain to the patients the reason for changing their ARV regimen and the drugs should be available at all the sites. Counselling and reassurance should be provided to HIV positive women in cases of stock-outs. HIV positive women should be encouraged to join support groups in order to share their experiences with others. Those with social problems should be referred to social workers for further interventions. Health care workers should be taught on how to treat HIV positive women with compassion and sensitivity. There is need to provide food parcels and income generating projects to HIV positive women so that they will be able to adhere to their ARV treatment.

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## APPENDICES



## APPENDIX 3

# Informed Consent form

## Section A: Research Information for Adults Participants

### An invitation to participate in a Study

You are kindly invited to take part in a study being conducted by Felistus Kwanisai, a postgraduate student in the Department of Social Work and Criminology at the University of Pretoria. This study is being conducted in partial fulfilment of the MSW (Health Care) degree requirement.

### Title of the Study

Antiretroviral Treatment: Challenges experienced by HIV positive women in Zimbabwe.

### Purpose of the Study

This study is about understanding the challenges and experiences of HIV positive women in Zimbabwe when it comes to accessing and adhering to ARV treatment. Information on HIV and AIDS is normally on the causes of the disease and the prevention methods. Instead, this study would like to hear the whole story of your experiences as far as accessing ARV treatment is concerned from the time you were diagnosed with the disease until now.

### Procedures

Should you agree to participate in the study, you will be asked to take part in an audio taped semi-structured interview. The interview will take place at a time and place that is good for you and it will approximately take one hour to one and half hours to complete. Data collected from the interview will be used strictly for research purposes only.

### Potential Risks

Because the study is about you and your experiences, the main risk is your feelings when you are telling it. Your story might be very sensitive and personal and you might feel

uncomfortable telling it to the researcher. Please be advised that you are in control all the time, you can stop the interview or leave anytime. You are free to ask any questions, phone the researcher at any time or cancel your agreement to take part in the study.

### **Potential Benefits**

You will not be compensated for your participation in this study. You will not benefit directly from the study.

### **Your Rights**

The study will do utmost to ensure that your rights are upheld and respected. Your participation in this study is voluntary. You may refuse to answer any questions or withdraw from the study at any time for any reason without incurring any negative consequences. You also have a right to ask any questions, voice any problems or issues at any time either during the interview or telephonically.

### **Confidentiality**

All the information that you provide will be treated in a confidential manner. Your identity will remain anonymous and will therefore not be linked to any of the audio taped responses, transcripts or the final report. The records and work derived from the study will be handled by the main researcher only and will also be kept in a secure place for 15 years at the University of Pretoria. The data you have shared will be destroyed should you choose to withdraw from the study so that your privacy may be kept. A written consent letter will be requested from you as a participant should it be necessary to share or use the information with anyone outside the research context.

### **Access to the Researcher**

If you have any questions, queries or concerns or anything else relating to the study, please do not hesitate to contact the main researcher. A copy of this letter will be given to you for your keeping.

**Researcher:** Felistus Kwanisai

**Contact Numbers:** 0779 499 731 or +2771 872 9087

**Email:** fellykwany@gmail.com

Thank you for your cooperation. Please may you sign the consent form on the next page to indicate that you have read and understood the information provided above and that you have voluntarily agreed to participate in the study.

Kind Regards

---

**Ms Felistus Kwanisai**

**Researcher**

## Section B: Consent Form for Adults Participants

I \_\_\_\_\_ (Full names and Surname of Participant hereby freely give permission to take part in the study voluntarily as explained in Section A. I have read the contents of Section A of this letter and understand the purpose of the study and my potential role in it.

**Participant:**

**Signed:**

**Date:**

**Name in Print:**

**Contact Number:**

**Researcher**

I have explained the study to the participant, and provided her with a copy of the participant information sheet.

**Signed:**

**Date:**

**Name in Print:**

**Contact Number:**

**Witness:**

**Signed:**

**Date:**

**Name in Print:**

**Contact Number:**



UNIVERSITEIT VAN PRETORIA  
UNIVERSITY OF PRETORIA  
YUNIBESITHI YA PRETORIA

Faculty of Humanities  
Office of the Deputy Dean

6 December 2012

Dear Prof Lombard

**Project:** Antiretroviral Treatment: challenges experienced by HIV positive women in Zimbabwe  
**Researcher:** F Kwanisai  
**Supervisor:** Dr CL Carbonatto  
**Department:** Social Work and Criminology  
**Reference number:** 10411802

I am pleased to be able to tell you that the above application was **approved (with comment)** by the **Postgraduate Committee** on 13 November 2012 and by the **Research Ethics Committee** on 29 November 2012. 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

A handwritten signature in blue ink, appearing to read 'E. Taljard'.

**Prof Elsabé Taljard**  
**Acting Chair: Research Ethics Committee**  
**Faculty of Humanities**  
**UNIVERSITY OF PRETORIA**  
e-mail: [elsabe.taljard@up.ac.za](mailto:elsabe.taljard@up.ac.za)

## **Interview Schedule- Shona Version**

### **Research for MSW (Health Care)**

**Principal Investigator: Felistus Kwanisai (10411802)**

**Musoro: Matambudziko anosanganikwa nawo nemadzimai ane chirwre cheHIV and AIDS (shuramatongo) pakuwana mapiritsi ekuderedza utachiona Mumuviri (emaARVS) muZimbabwe.**

#### **1. Mubvunzo yekutanga maerereano nechirwre che HIV and AIDS**

**(Shuramatongo), marapirwo acho uye maARVs.**

- Makore ekuberekwa
- Kuroorwa, kufirwa nemurume kana kuti kune shamwari rume yamunofambidzana nayo.
- Dzidzo yenyu
- Nzira yenduramo- kushanda kana kushanda
- Nguva yareba zvakadii yekurarama nechirwre cheHIV and AIDS (Shuramatongo)
- Nguva yareba zvakadii muri pachirongwa chemapiritsi emaARV uye makatanga kumamwa rini.
- Nhorondo yekuziva, kubatwa uye kugamuchira kuti mune chirwre cheHIV and AIDS (Shuramatongo).
- Nderupi ruzivo rwamakawana kubva kune vehutano maererano nechirwre HIV and AIDS (Shuramatongo) uye mapiritsi emaARV.
- Makabuda pachena here kumhuri yenyu kuti mune chirwre-ndiani wamakatanga kuudza,
  - akazvitora sei
  - Makanzwa sei pamakapedza kubuda pachena

#### **2. Mafungiro evanhu munharaunda uye evakadzi vane chirwre HIV and AIDS (Shuramatongo) maererano nezvechirwre HIV and AIDS (Shuramatongo) uye mapiritsi emaARV.**

- Nzwisiso yezvechirwre cheHIV and AIDS nehonzero yacho
- Nzwisiso pamusoro pemapirirwo echirwre cheHIV and AIDS - chinorapika chichipera here.
- Maonerwo uye rusarura rwunoiwa kuvanhu vane chirwre cheHIV and AIDS mumatunhu.
- Kutaurirana nababa kana shamwari rume kushandisa zvidziviro pamunosangana pabonde
- Baba kana shamwari rume yakaongororwawo here uye iri pachirongwa here chemapiritsi emaARV
- Maonerwo uye marapirwo echirwre cheHIV and AIDS nen'anga uye maporofita
- Mamiriro ematongerwo enyika nekuwanikwa kwemapiritsi emaARVs kuvakadzi vane chirwre che HIV and AIDS

### **3. Zvinosanganikwa nazvo nevakadzi vanorarama nechirwere cheHIV and AIDS (Shuramatongo)**

- Kuwanikwa kwemapiritsi emaARV nezvime zvirwere zvakanangana kana kuti zvinokonzerwa neHIV and AIDS kuvakadzi vane chirwere
- Pane mari yamunobhadhara here pamunoenda kunotorwa mapiritsi emaARV- mari yekuti mubatsirwe
  - kutenga imwe mishonga yezvime zvirwere zvakanangana kana kuti zvinokonzerwa nechirwere cheHIV and AIDS
- Kuwanikwa kwechikafu chinovaka muviri uye nemvura yakachena
- Nzvimbo dziriko dzakawanda here dzinotorerwa mapiritsi emaARVs uye nehurefu hwadzo-dziri pedyo here kana kuti dziri kure
- Masvikirwo ekunzvimbo dzinowanikwa mapiritsi emaARV- munoshandisa chifambiso here kana kuti munofamba netsoka
- Nguva inomirwa mumutsetse kusvika murapi azokubatsirai uye nekukupai mapiritsi emaARV- mitsetse yakareba here kana yakaringana
- Kuwanikwa kwemapiritsi ese emaARV- kushaikwa kwawo or kweimwe mhando
- Kuchinjwa kwemapiritsi emaARVs- kune zvakanokonzerwa here (zvazvakanakira nezvazvakashatira)
- Kuendeswa kunowedzerwa kuongororwa kweutachiona- kuchipatara chikuru chemudunhu kana chemuPurovhinzi.
- Rutsigiro rwunowanikwa kubva kumhuri nevanhu vemunharaunda- rutsigiro rwepanyama nemifungwa
- Dzidziso nezvamashandiro emapiritsi emaARV uye nezvaanonzwisa kana zvaanonkonzerwa pakumwiwa kwawo
- Dzidziso maererano nekutevedzera kumwiwa kwemapiritsi emaARV zuva nezuva usingadarikire
- Kuringana kwevarapi panzvimbo dzinopiwa mapiritsi emaARVs- hushomeko hwavo
- Maonero anoita varapi kuvakadzi vanechirwere cheHIV and AIDS

### **4. Zvingadiwa pamarapiro emapiritsi emaARV**

- Rubatsiro rwungadiwa nevakadzi vanechirwere cheHIV and AIDS maererano nemashandiro kana marapiro emapiritsi emaARV
- Nzvimbo dzakawanda dzinogovera mapiritsi emaARV
- Marapiro akakwana kubva kuvarapi
- Zvime zvinhu zvingadiwa nevakadzi vane chirwere cheHIV neAIDS

### **5. Zvinokurudzirwa**

- Zvingakurudzirwa kune vamwe vakadzi vane chirwere cheHIV and AIDS

## **APPENDIX 4**

### **Interview Schedule**

#### **Research for MSW (Health Care)**

**Principal Investigator: Felistus Kwanisai (10411802)**

#### **Antiretroviral Treatment: Challenges experienced by HIV positive women in Zimbabwe.**

##### **1. HIV and AIDS and Antiretroviral treatment- General**

- Age.
- Marital status- married, single, widow or in a stable relationship
- Level of education
- Economic status- employed or unemployed
- Period of living with the disease
- How long and since when you started taking antiretroviral treatment
- Diagnosis of HIV a person with HIV and AIDS- how did you find out that you are HIV positive.
- Information regarding HIV and AIDS and ARV treatment received
- Disclosure to the family- the first person you spoke to
  - the person's reaction
  - how did you feel after disclosure

##### **2. Societal and HIV positive women's views regarding HIV and AIDS and Antiretroviral treatment**

- Understanding the nature of the disease and its causes
- Understanding the treatment of HIV and AIDS- is it curable
- Stigma and discrimination associated with the disease.
- Negotiation for safer sex
- Partners getting tested and also taking the ARV treatment
- Traditional and faith healer's diagnosis and treatment of HIV and AIDS
- Antiretroviral treatment and the political situation in the country

##### **3. Experiences of being an HIV positive woman**

- Access of HIV positive woman to ART and HIV- medication for opportunistic infections
- Any payment made at the ARV treatment sites- consultation fee
  - buying other drugs for OIs
- Affordability of a good nutrition and access to clean water
- The availability of ARV treatment sites and the distance- too close or too far
- Accessing the ARV treatment site- walking or use transport
- The time which they wait before they receive treatment at the ARV treatment sites- long or short queues.
- The availability of ARV regimen- stock outs or not having the whole regimen

- Change of ARV regimen- any effects (positive or negative)
- Referral for diagnostic assessments- District or Provincial Hospitals
- The support received from the family or community- emotionally and materially
- Education on ARV treatment and its results- side effects
- Education on importance of adherence
- Availability of healthcare workers at the ARV treatment sites- any shortage
- Attitude of healthcare workers towards women with HIV and AIDS

#### **4. Needs related to Antiretroviral treatment**

- Assistance needed by HIV positive women in terms of Antiretroviral therapy
- Sufficient ARV sites
- Adequate treatment from health care workers
- Any other needs identified by HIV positive women

#### **5. Recommendations**

- Recommendations to other HIV positive women



# BHASO

## Batanai HIV & AIDS Service Organisation

6 Rekayi Tangwena Ave Box 1707 Tel/Fax: +263 39 264 960

PVO 16/96

Cell: 0773 514 292/0772 405 790 Email: batanai@bhaso.org Web: www.bhaso.org

15 August 2012

THE UNIVERSITY OF PRETORIA

REPUBLIC OF SOUTH AFRICA

TO WHOM IT MAY CONCERN

**RE: CONFIRMATION OF RESEARCH**

This letter serves to confirm that the bearer; FELISTUS KWANISAI, has been granted permission to carry out her research on HIV and AIDS, women and treatment with support from BHASO and its target groups that include people living with HIV and women.

Sincerely

Peter Marimi

Training & Information Officer





# REFORMED CHURCH IN ZIMBABWE

COMMUNITY BASED AID PROGRAMME CELL: 0712 875252  
P O BOX 1151 CELL: 0773268183  
MASVINGO Email: rczchap@gmail.com

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The Supervisor  
University of Pretoria  
Faculty of Humanities  
Department of Social Work and Criminology

28 June 2012

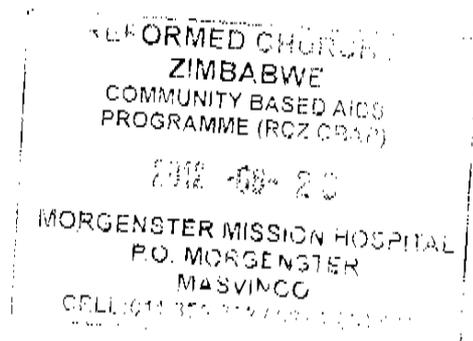
**REF: PERMISSION TO PERFORM EMPIRICAL RESEARCH: FELISTUS  
KWANISAI (10411802)**

Permission is hereby granted to Felistus Kwanisai to perform empirical research in our organisation the Reformed Church Community Based AIDS Programme (RCZ CBAP) on the challenges experienced by women with HIV and AIDS with regard to antiretroviral treatment in Zimbabwe.

Kind regards

Samuel Mhungu

RCZ CBAP Coordinator.





**UNIVERSITEIT VAN PRETORIA  
UNIVERSITY OF PRETORIA  
YUNIBESITHI YA PRETORIA**

**FACULTY OF HUMANITIES  
RESEARCH PROPOSAL AND ETHICS COMMITTEE**

**Declaration for the storage of research data and/or documents**

I/ We, the principal researcher(s) Felistus Kwanisai\_\_\_\_\_

and supervisor(s) Dr C.L. Carbonatto\_\_\_\_\_

of the following study, titled Antiretroviral Treatment: Challenges experienced by HIV positive women in Zimbabwe\_\_\_\_\_

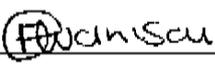
will be storing all the research data and/or documents referring to the above-mentioned study in the following department: Social Work and Criminology\_\_\_\_\_

**We understand that the storage of the mentioned data and/or documents must be maintained for a minimum of 15 years from the commencement of this study.**

Start date of study: March 2010\_\_\_\_\_

Anticipated end date of study: November 2013\_\_\_\_\_

Year until which data will be stored: December 2013\_\_\_\_\_

Name of Principal Researcher(s)	Signature	Date
Ms Felistus Kwanisai		08/10/2012

Name of Supervisor(s)	Signature	Date
Dr CL Carbonatto		

Name of Head of Department	Signature	Date
Prof A Lombard		