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THE LIVED EXPERIENCES OF HIV-POSITIVE WOMEN IN POVERTY

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by

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DECLARATION

I declare that **THE LIVED EXPERIENCES OF HIV-POSITIVE WOMEN IN POVERTY** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before any other degree at any other institution.

SIGNATURE
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DATE

ABSTRACT

The focus of this study was on the experiences of a small sample of local women who are HIV-positive and are living in poverty. The researcher was interested in exploring the psychological and social experiences of these women using Interpretive Phenomenological Analysis. This research aimed at giving these women a voice to express their first-hand, personal accounts of living with HIV in poverty. Data was analysed for meaningful units, which were interpreted inductively and hermeneutically, and categorised into super-ordinate themes. Six themes within the participants' experiences of living with HIV were determined, namely: (1) experiences of diagnosis, (2) disclosure experiences, (3) stigma, (4) ARV experiences, (5) experiences of social support and (6) poverty. This research found that after an HIV-positive diagnosis, most women experience a variety of emotional reactions. These reactions however seem to change overtime into positive acceptance of the HIV diagnosis. Most of the women in this study preferred to use partial disclosure than to fully disclose their HIV-positive status openly to families, friends and to their community. Reasons for not using full disclosure included fear of discrimination and stigma, which included a fear of being rejected or being blamed for their status and a fear of losing relationships. It was also evident from the findings that most of the women had experienced stigma directly and therefore partial disclosure was used as a coping mechanism to protect the self from further harm. It was also revealed that stigma not only has a negative impact on disclosure but also on social support and ARV experiences. Because of HIV-related stigma, lack of social support was a struggle that almost all the women in this study had experienced. Lack of understandings about their medication also had a negative impact of the ARV experiences. Stigmas along with poverty are the major struggles that HIV-positive women have to deal with in their day to day living. The findings of this study reveal a need for further research in this experiential area as well as campaigns and education around issues such as stigma, medication, and emotional difficulties associated with HIV.

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CHAPTER 1: INTRODUCTION

1.1 Introduction

Sub-Saharan Africa carries the burden of the world's HIV infections, where women in particular are increasingly affected (Jewkes, 2009). Within the sub-continent, South Africa has one of the highest HIV prevalence in the world and the largest number of people who are HIV-positive (Ackerman, & de Klerk, 2002). According to Jewkes (2009), young women in the age group 15 to 24 years account for 90% of recent HIV infections, and the incidence of infection peaks in the 20 to 29 year age group, where women are six times more likely to become infected than men.

Women are said to be at greater physical risk for HIV infection than men, and are twice more likely to be infected by HIV through unprotected intercourse than their male counterparts (Ackerman, & De Klerk, 2002). Other factors that account for higher infection rates amongst women are social, these include: high unemployment rates, gender inequality, migration and lack of education that disempower women – and all factors associated with poverty. (Hattingh, Walsh, & Joubert, 2009).

Receiving an HIV-positive diagnosis can evoke numerous traumatic reactions. These reactions can include a fear of dying, uncertainties related to disclosure and others' responses to their HIV-positive status, uncertainties about starting treatment for HIV/AIDS, worrying about opportunistic infections, a fear that relationships with others will deteriorate, difficulty with family dynamics, and emotional as well as physical violence, all of which might contribute to feelings of depression, anxiety and guilt. Following these fears and reactions, HIV-positive people are faced with the difficulty of deciding whether to disclose or not to their families, friends and sometimes health care providers (Makin et al., 2008). In all relationships the potential for rejection and discrimination can result in feelings of mistrust. This often leaves those infected alone and distanced from their families, friends and colleagues. Due to the stigma and discrimination associated with HIV, the dilemma of deciding who to tell and how to tell is very difficult for an HIV-positive person. Since disclosure can contribute to reactions of rejection it is often impossible to judge how people are going to react, thus leaving HIV-positive individuals isolated and destitute (Makin et al., 2008).

Even though there is now improved access to antiretroviral medication, living with a serious and life-threatening disease like HIV is likely to be stressful and difficult. HIV-positive individuals may stay physically healthy for many years but misperceptions and fears about HIV/AIDS is still widespread in the general public, causing social and emotional difficulties for infected people (Jones, 2005). Globally, reactions around the HIV/AIDS epidemic have ranged from silence to denial, to hostility and violence. Fear of being labeled or socially excluded may prevent women from getting tested for HIV or disclosing their HIV-positive status, therefore preventing them from protecting their partners and seeking support (Jewkes, 2009).

The focus of this study is on the experiences of HIV-positive women in poverty. The relationship between HIV and poverty is complex and multi-dimensional (Shisana, Zungu & Pezi, 2009). In South Africa, with high levels of inequality, socio-economic status is related to HIV risk, while HIV places a very heavy burden on those who are poor (Shisana et al., 2009). While there are competing definitions of poverty, for the purpose of this research, poverty is defined as “a condition characterised by severe deprivation of basic human needs, including food, safe drinking water, sanitation facilities, health, shelter, education and information. It depends not only on income but also on access to social services” (Noble, Ratcliffe, & Wright, 2004, p. 6).

Families of an infected person feel the impact through expensive health care costs and, in cases when the infected are breadwinners, loss of income is often the result (Noble et al., 2004). Poverty affects one’s health and ability to access health care resources to treat infections (Shisana et al., 2009). At times poor people die as a result of not having easy access to health facilities. Shisana et al. (2009) reports that poor living conditions increase the risk of secondary infection with opportunistic diseases such as TB, a serious medical complication for people living with HIV. Poor living conditions also make antiretroviral drug (ARV) compliance more difficult because people are sometimes unable to have proper meals to take their medication. This places HIV-positive people at risk of developing AIDS (Shisana et al., 2009).

While poverty deprives people of opportunities to obtain quality health care, it also places people at risk of HIV infection in the first place (Shisana et al., 2009). It is claimed that many people living in poverty-stricken conditions are less concerned about long-term risk and they have little to lose by engaging in risky sexual behaviours for survival (Shisana et al., 2009). Jewkes (2009)

believes that while many of these women are aware of the dangers of unsafe sex, they are disempowered and less likely to be in a position to negotiate safe sex.

Unemployment and poverty deprive many black women of necessary goods such as food and housing. In order to overcome these barriers, young black women from rural areas often leave their home villages in pursuit of a better life in informal town and city settlements (Noble et al., 2004). Low literacy levels and limited business skills leave them with few job opportunities in their new environments. Transactional sex, where there is an expectation of material gain (as opposed to prostitution where there is a negotiated fee) is common (Jewkes, 2009). Additionally, migrant labour patterns tear families apart and increase HIV risk (Leclerc-Madlala, 2001). Females head most of the poor households and, in the face of increasing needs, some of these women may engage in multiple concurrent partnering, which involves transactional sexual activities, either occasionally or as professional commercial sex workers, thereby promoting a vicious cycle in the spread of HIV/AIDS. Out of desperation some parents encourage their daughters to become involved in multiple concurrent relationships as this might provide short-term financial relief for families (Shisana et al., 2009). Often it is older men who are employed and who have financial resources that are able to take advantage of this, and again, the inherent power imbalance means that the women are not often able to negotiate condom usage (Jewkes, 2009). Furthermore, older men have had longer sexual histories and more opportunities to have been exposed to HIV. Moreover, these men are likely also to have on-going sexual relationships with their wives and other peers, and so bring extensive sexual networks and multiple sexual concurrencies (Jewkes, 2009). These behaviours are rooted in poverty, and failure to see them as such is tantamount to victim blaming (Shisana et al., 2009). As a rural African woman has stated, “AIDS may kill me next month or next year, but hunger will kill me and my kids tomorrow” (Fuller, 2008, p. 91).

It is also important to look at cultural norms and beliefs that put vulnerable women at heightened risk for HIV infection (Harrison, 2008). For example, the traditional practice of paying lobola (bridal wealth) gives men considerable rights over their wives (Macleod-Downes, Albertyn, & Mayers, 2008). However, market forces and unemployment put the price of lobola out of the reach of many men, who consequently opt out of marriage. Harrison (2008) argues that the inevitable result is relationships that are not formally recognised, and fathers who can take little

financial responsibility for their offspring. Mothers are saddled with the responsibilities of children without financial resources and must seek financial support, which may include transactional sex. Also, the expectation that women should bear children in marital relationships to prove their worth, where lobola has been paid, precludes sexual protection (Castle, & Kiggundu, 2007). Research shows that widowed wives are sometimes blamed for infecting their late husbands, and often deserted by their in-laws and left with the responsibility of providing for their dependants (Shisana et al., 2009).

Thus gender inequality, which at times is culturally endorsed, places women at risk, because they are reliant on men financially and subjected to male domination, which is oftentimes based on threat of physical violence (Jewkes, 2009). Violent and controlling men, in particular, are associated with increased HIV risk in women, primarily as a result of the powerless climate they create. Jewkes (2009) reported that women with low self-esteem and who are financially dependent on their male partners are less able to negotiate condom usage because they fear being accused of being unfaithful and fear the violence that this might provoke.

While many studies, typically quantitative, have explored the complex triadic relationship between HIV and poverty and gender, less emphasis has been placed on the actual lived experiences of women with HIV who live in conditions of poverty. Given the various factors that confer vulnerability on impoverished women in particular, a gendered approach to researching the lived experiences of HIV is crucial, especially approaches that privilege marginalised women's own accounts of their lives with HIV.

1.2 Problem Statement

The focus of the proposed study is on the experiences of a small sample of local women who are HIV-positive and are living in poverty. The researcher is interested in exploring the psychological and social experiences of these women using Interpretive Phenomenological Analysis. This research aims to give these women a voice to express their first-hand, personal accounts of living with HIV in poverty. The interviews will be conducted in their home language, which is something that is missing in many similar studies that are typically conducted in English or Afrikaans, often excluding those who are monolingual.

1.3 Definitions used in the Study

It is important to define at this point some of the key concepts which are significant to this thesis:

1.3.1 Women and Girls

This thesis uses the definition of 'women' which includes girls. This is based on the definition of women under the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (African Women Protocol). This definition is important in this thesis because within the context of HIV and AIDS, girls and women face related challenges (Amollo, 2007).

1.3.2 Sex and Gender

Sex refers to the biological or physiological differences between men and women, while gender signifies the differences that societies and cultures ascribe to people on the basis of their sex. Therefore, gender refers to a structural relationship of inequality between men and women that is reinforced by custom. A lot of the time the term 'gender' is used interchangeably with 'women' (Beasley, 1999).

1.3.3 Patriarchy

As a concept, patriarchy was first used by social scientists to describe a system of government where men held political power in their capacity as head of households. Patriarchy is a basic concept of radical feminists who used it to describe the social structures which allow men to dominate women (Beasley, 1999).

1.3.4 Violence against Women

The Declaration on the Elimination of Violence against Women defined violence against women as 'any act of gender-based violence that results in, or is likely to result in, physical, sexual, or psychological harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life' (Byrnes & Bath, 2008).

1.3.5 Gender-based Violence

This study relies on the definition of the term ‘gender-based violence’ as set out in the Committee on the Elimination of Discrimination against Women (CEDAW): ‘violence that is directed at a woman because she is a woman or that affects women disproportionately’. This definition is broad enough to also include violence committed against *men* based on their gender, although it is generally accepted that the vast majority of victims of gender-based violence are women (Byrnes & Bath, 2008).

1.4 Overview of the Study

This study consists of five chapters. Chapter 2 reviews literature specifically on HIV/AIDS, women and HIV, and poverty and HIV/AIDS. It also looks at the impact that patriarchy and economic dependence has on women, and violence against women. This chapter provides an overview of the psychological impact and physiological impact of living with HIV/AIDS, and social support as well as adherence are also discussed. In Chapter 3, a detailed description and justification of the qualitative methodology used in this study is provided. To provide a clear idea of how the research findings were obtained, sampling, data collection as well as data analysis will be discussed in this chapter. Additionally the validity of the study and ethical procedures will be discussed. Chapter 4 consists of a presentation of the research findings and discussions. Chapter 5 provides a conclusion of the entire study with critical evaluation and recommendations for further research will be presented in this chapter.

CHAPTER 2: LITERATURE REVIEW

2.1 The Sub-Saharan Pandemic

HIV/AIDS came to the attention of scientists over thirty years ago and since then 65 million people globally have been infected, while 25 million people are reported to have died of AIDS (Rohleder, Swartz, & Kalichman, 2009). The human immunodeficiency virus (HIV) which ultimately leads to the acquired immunodeficiency syndrome (AIDS) is the most serious epidemic affecting the world today, particularly for sub-Saharan Africa (UNAIDS, 2010). Within sub-Saharan Africa, HIV/AIDS has reached critical levels, where over 23 million people are currently infected with HIV (UNAIDS, 2010) and where women represented 61% of adults with HIV in 2007 (UNAIDS, 2009).

As noted, in sub-Saharan Africa, more women than men are living with HIV, and young women aged 15–24 years are as much as eight times more likely than men to be HIV-positive (UNAIDS, 2009). The UNAIDS (2009) reported that protecting women from HIV means protecting against gender-based violence and promoting economic independence from older men. Nattrass (2008) argues that the “feminization” of the epidemic is the consequence of the poorer socioeconomic status of women, as also observed by the Joint United Nations Programme on HIV/AIDS. Gender inequalities as well as gender norms and relations, including practices around sexuality, marriage and reproduction, and barriers to education, lack of access to health information and care, and inadequate access to economic, social, legal and political empowerment are major contextual barriers that women face in their everyday life (Dunkle et al., 2004a).

HIV/AIDS is reported to also have a massive impact on the productive core of the nation, which affects those who rely on their resources and support (Hodge, 2008). The consequence of such a phenomenon has extensive social, political and economic repercussions. HIV/AIDS has been reported to be a threat to human resources, as teachers, health care workers and civil servants have been dying faster than they can be trained (Bing & Cheng, 2008). This results in social instability, the breakdown of family and community support structures, hindering service delivery, and national security becomes threatened as military, police and other security forces have been dying from AIDS (Bing & Cheng, 2008). HIV/AIDS should not be viewed as a single

isolated phenomenon affecting global health, but rather it is a complex problem, which must be understood from the multiple dimensions in which it influences (Weeks, 1989).

2.2 HIV in the Context of South Africa

Around 1983 when HIV/AIDS was discovered in South Africa, it was mainly associated with homosexual men (Abdool Karim & Abdool Karim, 2010). During 1990 and 1994 it is reported that the epidemic rapidly increased within the heterosexual population, specifically black heterosexuals, exceeding the homosexual epidemic (Abdool Karim & Abdool Karim, 2010). It was first noticed in the urban areas and it progressively moved into the rural areas (Abdool Karim & Abdool Karim, 2010). The responses of previous South African governments were negligent (Nattrass, 2007). People were deprived of access to effective treatment because the government was in denial about HIV being a sexually transmitted disease leading to AIDS (Nattrass, 2007). This resulted in the HIV burden which South Africa is currently faced with. Since then South Africa is said to be home to the world's largest population of HIV-positive people, with an estimated 5.7 million of its citizens living with HIV (UNAIDS, 2009).

Recently it has been reported that HIV has shown stabilisation in the last six years, particularly among pregnant women attending antenatal clinics for the first time (UNAIDS, 2011). It is reported that in 2011 the HIV prevalence amongst pregnant women was 29.5%, showing a slight drop of 0.7% from that of the 2010 HIV prevalence (UNAIDS, 2011). According to UNAIDS (2011), it is estimated that the HIV prevalence nationwide among the general adult population between the ages of 15-49 years has also remained relatively stable at 17.3% since 2005. In 2011 the estimated percentage of new infections was 1.43% compared to that of 1.63% of new infections in 2008 (UNAIDS, 2011). Despite some encouraging signs, the rate of new infections is reported to be highest among young women; of the 23 million infected with HIV/AIDS, 60% are women (Hodge, 2008; UNAIDS, 2010). The vulnerability of women when it comes to HIV is said to be increased by their roles in heterosexual relationships (Jewkes, 2009).

2.3 HIV and Women

In South Africa, according to Jewkes (2009), young women in the age group of 15 to 24 years of age account for 90% of recent HIV infections, and the incidence of infection rises in the 20 to 29

year age group, where women are six times more likely to become infected than men. Women's increasing HIV prevalence rate has been identified as a significant health, social and economic problem facing South Africa. Data on HIV prevalence rates among South African women are mainly obtained from reproductive women who attend antenatal public health clinics, as discussed in the above section.

As mentioned, there are several factors that place women at greater risk than men. Women are physiologically more vulnerable to HIV and STDs than men (Harrison, 2008). The surface area and lining of the vagina means that the virus is more readily transmitted from men to women than from women to men, with women being twice as likely as men to be infected by HIV through unprotected intercourse (Ackerman, & De Klerk, 2002). Women are more vulnerable to most STDs because of the greater mucosal surface exposed to pathogens during sexual contact, especially young women because their genital tracts are not fully mature (UNAIDS, 2009). Also, for women, frequent pregnancies interfere with the immune system, placing them at high risk of infection (UNAIDS, 2009). Other factors that are physiological include menstruation and co-efficiency with other sexually transmitted diseases and infections, which occur more in women, and increase women's susceptibility to HIV infection (Mgalla, Wambura & de Bruyn, 1997). This is made worse by culturally sanctioned practices like dry sex and cross-generational sex (Fuller, 2008). Furthermore, it is more difficult to identify STDs in women than men and they often go untreated, which leads to continued infections and long-term complications (Mgalla et al., 1997). The consequences of this high rate of STDs for women includes higher levels of infertility, increased incidences of cervical cancer, and an increased risk of HIV infection. The underlying social and economic factors that contribute to women's vulnerability to HIV infection are huge. Other factors that account for higher infection rates amongst women include high unemployment rates, gender inequality, migration and lack of education that disempower women, all factors that are associated with poverty. (Hattingh, Walsh, & Joubert, 2009). Indeed, it is claimed that "poverty creates a social and environmental context that promotes the spread of HIV infection" (Kalichman et al., 2006, p. 1642). Other factors include the lack of economic power to access treatment or preventative measures such as condoms (Dunkle et al., 2004b). Most women who are unemployed are less worried about getting condoms or contraceptives than they are about their immediate survival needs. Jewkes (2009) argues that women generally lack

social power to make responsible sexual decisions; women generally rely on men to make sexual decisions on behalf of them. In most relationships men therefore tend to decide whether or not a condom will be used. Cultural values and practices also maintain and worsen the powerlessness of women in the face of the pandemic (Harrison, 2008). Furthermore, the issue of HIV and AIDS raises significant moral questions about human sexuality and relationships between women and men.

Dunkle et al. (2004a) suggest that HIV/AIDS is made worse by poverty, gender inequities, and the physiological make-up of women. It feeds off and aggravates pre-existing human rights violations in society such as gender inequality and socioeconomic exclusion and deprivation. Furthermore, apart from being a sexually transmitted disease, HIV and AIDS add another burden on people living with AIDS (PLWAs) in the form of stigmatisation (Deacon, Uys, & Mohlahlane, 2009). Besides devastating the social fabric through high levels of death and illness, HIV and AIDS has predominantly placed women in a situation of double jeopardy in the sense that apart from being viewed as containers of transmission, they are assigned to an inferior place in society, further prejudicing their position in a world that already disregards them in many ways (Dunkle et al., 2004). It has also been discovered that women's vulnerability has been made complex by other socio-cultural concerns such as the fact that health workers have a tendency to focus on the symptoms of the disease as it is shown in men; for example, mouth ulcers, tuberculosis, weight loss, while the gendered symptoms of the disease in women, such as persistent vaginal thrush and genital ulcers are often assumed to be symptoms of curable sexually transmitted diseases (Levison, & Levison, 2001). This resulted in several unreported AIDS-related deaths among women, as well as having serious consequences for the manner in which the virus and its manifestations is interpreted within the medical and social spheres (Mgalla et al., 1997). Not only do these tendencies indicate unequal access to medical care for women who are HIV-positive, they also highlight the gendered nature of medical training and the intrinsic biases against women in relation to the treatment of STDs, HIV and other sexually related problems (Mgalla et al., 1997). The increased physiological risk experienced by women in Africa is made complex by the HIV risk they tolerate from subordination, discrimination and inequality (Dunkle et al., 2004a). In most of Africa, sexually transmitted diseases still carry a great deal of stigma as they are sexually-related and considered to be women's diseases'. Occurrences across

the continent confirm the common belief that women are inherently sexually unclean and that they therefore cause sexually transmitted diseases (Leclerc-Madlala, 2001). There is no doubt that such stereotypes further prejudice women in the face of the epidemic. Of most importance has been the negative impact such beliefs have had on women's health statuses across most African cultures (Leclerc-Madlala, 2001). The general negative view around women's health have created a situation where the majority of women accept that they are carriers of the virus (Hattingh et al., 2009). As a result, women accept the idea that they are destined victims of the virus (Dunkle et al., 2004a).

2.3.1 Sex and Sexuality

Sex and sexuality are important in understanding the connection between women, HIV and AIDS (Bujra, 2000). The sexuality of men and women correlate in a manner that defines the way someone acquires HIV, the way it is managed and how the disease then impacts on men and women (Mgalla et al., 1997). This interaction verifies the important point that both the epidemiological and socio-cultural facets of HIV and AIDS have to be addressed accordingly. Sexuality is gendered by the reproductive, social, economic, political, cultural and religious roles people play as women and men in each society (Sanday, 1981). Sanday (1981) argues that female sexuality in all human societies is largely constructed in relation to a perceived male sexuality and pleasure, and is intimately linked to reproduction. Women are socialised into a belief that their role is only to be a wife, a lover, a mother. These categorisations in turn become the context of vulnerability - for example, as a lover, she is expected to be sexually attractive and be desired by men; as a mother and wife, to be a care giver and provide sex upon demand from a husband (Jewkes, 2009). Sexuality is therefore the social construction of a biological drive. Sexuality also relates to the aspects of gender identity that relates to sex. It includes sexual desire, sexual behaviour and sexual orientation (Bujra, 2000). As far as sexual behaviour is concerned, men in many societies can be proud of having multiple partners because it is believed to show their sexual prowess (Jewkes, 2009). Jewkes (2009) reported that sexually transmitted infections may be viewed as acceptable 'battle scars' showing that a man has succeeded in 'getting his way' with a woman. Sex is for the most part about satisfying a man's sexual desires, essentially the husband, and about producing babies. Women who enjoy sex may be assumed not to be trusted and be seen as 'loose' and uncontrollable (Dunkle et al., 2004a). Hence sexuality

often refers to male needs and desires, while women's sexuality is looked down on, ignored or feared and repressed (Dunkle et al., 2004a).

In South Africa issues around sex, sexuality and HIV/AIDS have assumed a specific character as a consequence of the long and excessive economic and political exploitation (Jewkes, 2009). Women in South Africa live in different racial, class, geographic, religious and cultural contexts. Geographical displacement during apartheid played a major role in sustaining black women's subordination. Over four million black people were displaced from urban to rural areas designated as 'homelands' for the different ethnic groups. In addition, within the urban areas black people were moved from designated 'white spots' to designated 'black spots' (Fourie, & Meyer, 2010). These were mainly grossly disadvantaged areas on the periphery or outside the urban areas. The effect of all of this was to create an enormous reservoir of people in the barren rural area with little hope of work or even a subsistence existence. By the nature of apartheid, these areas were also deprived of health and educational facilities. In such areas it was very difficult to inform the communities of the dangers of HIV and AIDS, and how to prevent its spread (Fourie, & Meyer, 2010). Furthermore, there was no infrastructure or facilities to do so. Also, migratory labour in South Africa allowed a situation to grow that provided a breeding ground for HIV and AIDS. Black workers were brought in from the homelands to supply the mines and industrial complexes in the urban areas (Shisana et al., 2009). They had to leave their families behind as they were not allowed to bring them with them, and they lived in overcrowded, basic single-sex hostels with little opportunity to study or for recreation. Such a situation inevitably led to sexual activity with multiple partners, as many men took on sexual partners at their places of work and then resumed their sexual relationships with their partners when they returned home.

Women were to be at the centre of this socioeconomic and political dispossession (Jewkes, 2009). Over the past century, hundreds of thousands of women have moved from the rural areas where their men had been forced to go. This contest against forced 'villagisation' resulted in a reconstruction of sexuality vis-à-vis traditionally defined sexual norms, as well as in relation to the urban milieu (Fourie, & Meyer, 2010).

Following the breakdown of apartheid and the ensuing democratic elections, the pass laws were abolished, and people had the right to move where they pleased (Fourie, & Meyer, 2010). This caused an influx of individuals and families into 'informal settlements' which often had no water, electricity or sanitation, and minimal health and educational services. The impact on this demographic change on the spread of HIV is self-evident. The often single, female-headed household emerged as women broke free of the traditional requirement that men head households (Shisana et al., 2009). The manner in which women related to men in this context signified a new sexuality. This exploration leads to the logical conclusion that the gendered constructions of sex and sexuality form part of the problem in the context of HIV/AIDS. This calls for a change of attitudes and socialisations.

2.4 Poverty and HIV/AIDS

The HIV/AIDS pandemic is no longer only a symptom of poverty, but it has also emerged as one of the most obvious causes of poverty in recent times, particularly in developing countries such as South Africa. Essentially, many studies in South and Southern Africa have clearly confirmed that poverty contributes to a rise in HIV infections (Shisana et al., 2009). One reason is that HIV infections are costly because many of the opportunistic infections associated with it (TB, pneumonia, and others) are expensive to treat. As such, HIV has not only caused many people in the developing world to be unable to contribute productively to their households' livelihoods, but many of the infected have become a drain on their families' financial resources (UNAIDS, 2009). Furthermore, thousands have died as a result of poverty, consequently imposing devastating shocks and stresses on the livings of those remaining behind. In fact, many households have ceased to exist because of AIDS deaths (Shisana et al., 2009). Those affected households that struggle on, often headed by females or orphans, typically suffer poverty because they are usually characterised by insufficient capacity to generate meaningful income (Shisana et al., 2009).

Mahal & Rao's (2005) study is one of the best cases that can be utilised to support the impact that poverty has on HIV. They found that medical treatment expenses constituted a significant financial burden for a sample of affected households in South India, with roughly 40-70% of HIV/AIDS-related expenditures being financed by borrowing. Similarly, studies of HIV/AIDS-

affected households in African countries such as South Africa and Zambia show that their monthly income fell by 66%-80% because of coping with HIV/AIDS-related illness (UNAIDS, 2009).

Families of an infected person feel the impact through expensive health care costs and, in cases when the infected are breadwinners, loss of income is the result (Noble et al., 2004). Poverty affects one's health and ability to access health care resources to treat infections (Shisana et al., 2009). At times poor people die as a result of not having easy access to health facilities. Shisana et al. (2009) report that poor living conditions increase the risk of secondary infection with opportunistic diseases such as TB, a serious medical complication for people living with HIV. Poor living conditions also make ARV compliance more difficult because people are sometimes unable to have proper meals to take their medication. This places HIV-positive people at risk of developing AIDS (Shisana et al., 2009).

While poverty deprives people of opportunities to obtain quality health care, it also places people at risk of HIV infection in the first place. Poverty appears to play an important role in influencing sexual decision-making by limiting individuals' decision-making powers in sexual relationships (Shisana et al., 2009). It is claimed that many people living in poverty-stricken conditions are less concerned about long-term risk and they have little to lose by engaging in risky sexual behaviours for survival (Shisana et al., 2009). Jewkes (2009) believes that while many of these women are aware of the dangers of unsafe sex, they are disempowered and less likely to be in a position to negotiate safe sex. Unemployment and poverty deprive many black women of necessary goods such as food and housing. In order to overcome these barriers, young black women from rural areas often leave their home villages in pursuit of a better life in informal town and city settlements (Noble et al., 2004). Low literacy levels and limited business skills leave them with few job opportunities in their new environment. Transactional sex, where there is an expectation of material gain (as opposed to prostitution where there is a negotiated fee) is common (Jewkes, 2009). Additionally, migrant labour patterns tear families apart and increase HIV risk (Leclerc-Madlala, 2001).

Poverty contributes to risky sexual practices as a result of a lack of knowledge and a lack of access to means of protection (Jewkes, 2009). It has been reported that the nature of the

relationship between poverty and HIV/AIDS is complex, e.g. how labour migration, worsened by rural poverty, can increase the spread of HIV/AIDS and how poor single mothers may be forced to become occasional sex workers in order to survive (Shisana et al., 2009). A great deal of research done on sexual behaviour argues that poor women, who are aware of HIV transmission and prevention, may be predominantly susceptible to HIV infection because of their continued high-risk sexual practices, usually in exchange for economic and financial security. This, it must be stressed, is the result of how 'women' are socialised generally to be dependent on men for material and economic resources (Ackerman & De Klerk, 2002). Poverty and limited economic opportunity contribute to the increase in HIV infection rates in women since sex turns out to be a sustainable income opportunity for those women who are most vulnerable to infection.

Young women whose opportunities for education and employment are severely restricted may also use transactional sex to help achieve higher status in youth cultures that prioritise sexual success and conspicuous consumption (Dunkle et al., 2004b). Transactional sex occurs in different types of sexual relationships. Studies among South African youth find that young women often receive gifts from primary dating partners. While these gifts are rarely the sole motivation for the relationship, they do provide an incentive for young women to both have sex and eschew condom use (Jewkes, 2009). Sometimes a woman has sex in the hope of establishing an on-going relationship that never materialises, but 'once-off' sex may also be a 'thank you' for drinks bought in a shebeen (Dunkle et al., 2004b).

2.5 Patriarchy and Economic Dependence

Thomas (2007) suggested that the essential reasons that hinder women's ability to protect themselves in relationships are their lower status in society and their financial dependence on men. In South Africa, it has been reported that there is a strong cultural belief that a man cannot and should not control his sexual desire (Jewkes, 2009). Infidelity is common when a man stays away from home over a long period. 'Chasing after women' is societally accepted as an important behavioural consequence of masculinity, and the need for 'skin-to-skin sex' is perceived as an essential requirement for health and wisdom (Jewkes, 2009). For most women negotiating condom use is not easy, even for educated and financially independent women. Within marriage suggesting condom usage is often interpreted as questioning the man's authority

and suggesting that he is being unfaithful and promiscuous. Women are perceived to be compliant, submissive and dependent, whilst men are perceived to be superior, and have more leadership and decision-making skills than women. These gender-specific qualities function as justification of men's dominant behaviour over women and fail to sanction behaviour that deems women powerless in their sexual relationships (Thomas, 2007).

It has been reported that men believe that it is a woman's responsibility to protect both partners from HIV (Dunkle et al., 2004a). Women are, then, often blamed for infecting others, as they are seen as the 'carriers of disease' (Makahye, 2005, p. 325). Yet men are said to most likely be in control of condom use and sexual initiation and show their sexual prowess through having multiple partners. Condom use is reported to increase levels of violence in sex-work (Jewkes, 2009). In a study of sex-workers working at truck stops on the route between Durban and Johannesburg (Abdool Karim, Abdool Karim, Soldan, & Zondi, 1995) it was found that many sex-workers did not use condoms with clients because this frequently led to violence as condom use left clients unsatisfied with the sex. Further, it was reported that clients were only willing to pay a quarter of the price for sex with a condom. Sex-workers are reported as not being unique in their problems pertaining to sexual negotiation. In other studies it has been concluded that condom use in personal situations may be seen as a break of trust and intimacy and brings an element of uncertainty to the sexual relationship for both sex-workers in non-sex-work related relationships and non-sex-working women (Jewkes, 2009).

2.6 Violence against Women

South Africa has the highest rate of gender-based violence in the world (Dunkle et al., 2004a). As noted, gender inequality is said to be in favour of men, giving them more power to control women and sexual encounters; this means that men generally control when and how sex must happen, using force whether physical or emotional (Jewkes, Sikweyiya, Morrell & Dunkle, 2011). Gender inequality, which at times is culturally endorsed, places women at risk because they are reliant on men financially and subjected to male domination, which is oftentimes based on threat of physical violence (Jewkes, 2009). Violent and controlling men, in particular, are associated with increased HIV risk in women, primarily as a result of the powerless climate they create. Jewkes et al. (2009) reported that women with low self-esteem and who are financially

dependent on their male partners are less able to negotiate condom usage because they fear being accused of being unfaithful and fear the violence that this might provoke. For women who have been abused, the fear of provoking attack may create a context in which risk reduction cannot practically be attempted. For example, Jewkes et al. (2011) suggest that fear of eliciting physical or sexual violence can prevent women from attempting to negotiate changes that go against a partner's wishes. Most remarkably, the occurrence of rape in violent relationships speaks to the dangers inherent in the sexual life of these couples and to the lack of power abused women have about sexual problems (Jewkes et al., 2011)

Supporting the idea that women in violent relationships are less likely to take precautions during sex, a history of partner abuse was associated with depression, which in turn was related to behavioural risk. Likewise, past abuse was associated with passive coping style, recent partner abusiveness, recent forced sex, and coercion not to use condoms (Jewkes et al., 2011). It has been reported that women in physically abusive relationships reported having less say about safer sex, engaging in unwanted sex frequently, and having lower self-efficacy for getting their partners to use condoms (Jewkes, 2009).

Dunkle et al. (2004b) argues that risk of HIV infection can also be a result of childhood sexual abuse, which often later in life results in high-risk sexual behaviour, prostitution, and recurrent sexual assault. Alcohol abuse and drug use may contribute to violence against women and to the risk of HIV infection by increasing risk-taking behaviour and negatively influencing rational decision-making.

Sex-workers have been cited as being predominantly vulnerable to STDs including HIV infection as they participate in sex with multiple partners and lack access to economic resources and positions of power and as such may end up having to choose between economic survival and possible HIV infection (Dunkle et al., 2004b). Further, the violence that sex-workers are most likely to experience includes rape; women working on the streets, who have little recourse to criminal justice services, are often raped and this increases the possibility of HIV infection (Dunkle et al., 2004).

2.7 HIV-related Stigma

In ancient Greece, the word 'stigma' referred to a sign, a cut or scar in one's body, which labelled the individual as a person who was morally deviant and therefore deserved to be avoided, usually a slave, a criminal or a traitor, for example (Goffman, 1963). In the twentieth century, the word stigma was revised to refer to characteristics of a person that is deeply discrediting, and reduces him or her 'in our minds from a whole and usual person to a dirty, discounted person' (Goffman, 1963, p.3).

HIV/AIDS is often associated with people who lead promiscuous lives, with homosexuality, with sex workers and with intravenous drug users (Weiner, 1993). An HIV-positive person is too often automatically assumed to be 'gay', 'black', 'promiscuous', 'young' or 'non-religious' (Deacon et al., 2009). The negative and judgemental beliefs that are derived from these associations are compounded because HIV is preventable and considered by many to be contracted through 'irresponsible' and 'immoral' behaviours. HIV/AIDS is therefore seen as a consequence of what is commonly perceived as 'deviant and immoral lifestyles' (Deacon et al., 2009), which evokes feelings of anger, fear and shame, and prevent empathy (Weiner, 1993). Women are more likely than men to be stigmatised as promiscuous after they have disclosed their positive status (Simbayi et al., 2007); and black women who live in poverty, in particular, are subject to much stigmatisation as they are viewed as more promiscuous than any other group (Jewkes, 2009).

Pletzer (2003) states that having a label of HIV/AIDS is stigmatising on its own. Stigma can also be in the form of negative attitudes about the disease, as well as unfriendly and avoidant behaviours directed towards HIV-positive people (Pletzer, 2003). This means that HIV-positive people are not only dealing with a life-threatening disease, but have also fallen victim to discrimination. Deacon et al. (2009) indicate that stigma can generally go from physical isolation or exclusion, to verbal abuse, loss of important work and social roles, deprivation of resources and even reduced quality of healthcare. The nature of people's reactions to HIV and AIDS goes far beyond a fear of infection and reveal instead the nature of HIV/AIDS-related stigma as a social phenomenon (Gilbert, & Walker, 2010). According to Herek (1988), HIV and AIDS

stigma is socially constructed, and differs in different regions of the world where different groups are affected.

For the purpose of this study it is important to discuss some of the different types of stigma; these include felt, enacted, instrumental and symbolic stigma. Felt (or internalised) stigma is a term for the shame that a person can feel as a result of their situation (Goffman, 1963). Enacted stigma refers to the actual experience of abuse, rejection, discrimination and human rights violations that HIV-positive people may experience (Gilbert, & Walker, 2010; Skinner, & Mfecane, 2004). According to Skinner and Mfecane (2004) enacted stigma may result in loss of relationships or social support after the disclosure of a person's HIV-positive status. Instrumental stigma is the fear of casual transmission that causes some to avoid or isolate people who are HIV-positive (Perloff, 2001). Lastly, symbolic stigma is the moralistic shaming and blaming that is directed at those who are HIV-positive (Herek, 1990). It involves the symbolic use of the illness to convey derogatory attitudes to those marginalised groups associated with the illness.

The effect of stigma is that people choose not to be tested for HIV and/or conceal their status from others in the hope that they will limit the extent to which they experience discrimination (Visser, Makin, & Lehobye, 2006). This can lead, for example, to HIV-positive mothers choosing to breastfeed their babies despite medical advice so as to avoid disclosing their status to others (Peltzer et al., 2005). Negative reactions from people in their surroundings can be internalised by HIV-positive individuals (Visser et al, 2006). Gilbert & Walker (2010) believe that this internalisation is the worst impact of stigma on HIV-positive persons. Research shows that internalised stigma correlates with depression scores and substance abuse (Simbayi et al., 2007).

The stigmatisation of HIV and AIDS often results in lack of support for HIV/AIDS sufferers by parents, teachers and the general community (Campbell et al., 2005). The stigmatisation of people living with HIV makes many people unwilling to even associate themselves with HIV prevention efforts (Campbell et al., 2005). Indeed, many of the psychosocial consequences of HIV are not a direct and inevitable result of HIV infection but rather the way in which people treat those who are HIV-positive.

2.8 Psychological Impact of Living with HIV/AIDS

Individuals receiving or who have received an HIV diagnosis are said to experience extremely stressful and life changing psychological reactions. Women living with HIV have been found to report higher prevalence and severity of psychological distress symptoms than men (Worthington, Myers, O'Brien, Nixon, & Cockerill, 2005). Research had identified the following reactions: emotional distress, anxiety, fear, helplessness, hopelessness, loss of self-esteem, suicidal behaviour, shock, surprise and disbelief, deep sadness, denial, guilt and bereavement, disorientation and derealisation (Hult, Maurer, & Moskowitz, 2009).

These psychological reactions associated with the uncertainty experienced are expected characteristics of suffering a life-threatening illness. As HIV is unpredictable in nature it causes fear of the unknown when one considers the possibility of it developing into AIDS (Worthington et al., 2005). A host of factors that recently diagnosed individuals must consider include uncertainties related to disclosure and others' responses to their HIV-positive status, starting treatment for HIV/AIDS and worrying about opportunistic infections (Brashers, Neidig, & Goldsmith, 2004). Depression, anxiety disorders and substance related disorders have been identified as the three mental disorders that HIV-positive individuals are likely to suffer from; and these mental disorders are also reported to have a major influence on ARV adherence (Nel, & Kagee, 2011). According to Freeman, Nkomo, Kafaar, and Kelly (2008), HIV-positive individuals are more likely to suffer from mental disorders such as depression, compared to the general public. Women in particular are reported to be at great risk of mental disorders. It is suggested that more women suffer from depression than men. Another concern is having to deal with an HIV-positive status within intimate relationships, which can cause a lot of anxiety specifically for women as they are more likely to be blamed for 'carrying' the illness into the relationship and financial matters become a great concern (Burchardt, 2010). An understanding of the consequences and associated emotional responses to uncertainty will motivate psychological and behavioural activities directed towards managing uncertainty (Brashers et al., 2004). For example, individuals who perceive their uncertainty as a threat may actively or passively seek information to reduce anxious emotional responses. The act of information seeking is linked towards gaining knowledge that will benefit the individuals in their experiences of living with HIV/AIDS (Brashers et al., 2004). Managing and developing strategies to deal

with these uncertainties assist diagnosed individuals to continue to live normally within the context of a positive status. Suspended in such uncertainty, HIV-positive people are confronted with the realisation that in order to impede the onset of AIDS they should remain in good health. They are also confronted with the anxiety of looming death (Burchardt, 2010). Experiences of diagnosis break perceptions of normality and drive individuals towards a range of techniques to regain control of their lives (Burchardt, 2010). HIV-positive people may adopt strategies that prevent them from accessing treatment and support, as their need towards normality involves a disconnection with identification as someone living with HIV/AIDS. On the other hand other people living with HIV may willingly identify as HIV-positive to assist in the therapeutic healing process. Burchardt (2010) emphasises the variety of on-going processes people engage to cope with and deal with their HIV-positive status. Burchardt (2010) argued that these engagements can be active ways of managing and dealing with HIV, but that is all dependent upon the individual's identification with their positive HIV status and the level and form of social support received. This therefore suggests that individuals can choose to dissociate with being HIV-positive to reject the idea that their HIV-positive status is an aspect of their identity. The decisions to integrate or dissociate with an HIV-positive status are strategies at reconstructing or avoiding stigmatising discourses relating to HIV (Brashers et al., 2004).

2.9 Physiological Impact of Living with HIV/AIDS

Without antiretroviral medicine, the progression of HIV to death from full-blown AIDS in South Africa can be as little as seven to eight years (Philips, 2004). The physiological effects of HIV/AIDS limit everyday activities, in so doing reducing health-related quality of life for those living with an HIV-positive status (Van As, Myezwa, Stewart, Maleka, & Musenge, 2009). Research conducted by Van As et al., (2009) indicates that South Africans living with HIV/AIDS experience impairments of mental functioning, a lack of energy, sleep deprivation, and emotional distress; as well as cardiovascular, hematological, immunological, and respiratory dysfunction. HIV infection is recognised as a multisystemic disease affecting multiple systems within the body (Worthington et al., 2005), and counteracts an individual's immunity thus rendering them vulnerable to opportunistic infections (Phillips, 2004). In South Africa the most prevalent opportunistic co-infection is tuberculosis, with 60% of those infected with TB having a co-infection of HIV (Daftray, Padayatchi, & Padila, 2007). Owing to the fact that no vaccine or cure

is currently available for HIV/AIDS, the only treatment means is through antiretroviral treatment, which is lifelong (Nwoye, 2004; Simon et al., 2006). It is therefore apparent that individuals who wish to lead healthier lives must adhere to continuous antiretroviral therapy (ART). Inadequate adherence to ART can result in increased HIV replication, high viral loads, and medicinal resistance (Nwoye, 2004; Simon et al., 2006). However adherence to ART is described as the most demanding, inflexible, and stringent of oral medications (Nwoye, 2004), the he medicines can cause often serious side-effects (DoH, 2013).

2.10 Guidelines for the Prescription of ARV Medicines

The newly revised WHO guidelines recommend that people should be started on ARVs when their CD4 count drops to 500 instead of 350 as this was the case previously. However, the South African Department of Health has only recently increased the CD4 cut-off from 200 to 350 for adults and adolescents (DoH, 2013). These guidelines also recommend that doctors immediately initiate ARVs for pregnant women living with HIV, people with TB and HIV, people with Cryptococcus meningitis or TB meningitis, and children living with HIV who are younger than five years irrespective of their CD4 count (DoH, 2013). The following are the benefits of taking ARV treatment:

- Suppress the virus
- Boost immune system
- Reduce death rate and prolong life of an HIV-positive person
- Delay further the development of opportunistic diseases (DoH, 2013).

The general principle for effective use of ARVs is adherence. They need to be taken at certain times consistently, to be taken on an empty stomach or full stomach and most importantly there should be careful monitoring and that includes drug interactions and side effects as per the guidelines by the DoH (2013). ARVs can have adverse side effects, sometimes minor and sometimes major. The side effects include headaches, tiredness, insomnia, dizziness or stomach aches and these are reported to go away within two weeks or three months of commencing treatment. The major side effects become problematic in the treatment of HIV as they sometimes lead to misshapeness and major discomfort leading to stopping of the treatment (DoH, 2013).

Most people diagnosed with HIV in the sub-Saharan region are said to prefer herbal mixtures before they start taking ARVs as they believe in traditional medicine and some continue taking these herbal remedies irrespective of being started on ARVs (Anderson, 2005). Because the South African government has taken time to provide ARVs this has contributed to the unwillingness of some HIV-positive people to start ARVs; consequently this has resulted in the increased use of traditional medicines or other herbal medicines like immune boosters (Anderson, 2005).

2.11 Barriers to ARV Adherence

HIV-positive people are required to adhere to their ARV treatment in order for their medication to work effectively in suppressing the viral load in their bodies (Kagee, 2008). Nel and Kagee (2011) believe that there are three types of factors which contribute to poor ARV adherence. The first factor they reported is that of treat regimen, which includes dosage and requirements of ingestion with specific foods. As most HIV-positive individuals live in poverty they are unable to afford healthy foods with which they are required to consume, this therefore makes it difficult for them to take their medication in the right way resulting in poor ARV adherence (Kagee, 2008). Toxicity and side effects are also reported to have a negative influence on ARV adherence. The second factor they reported was patient personal qualities, which refers to the emotional well-being of the HIV-positive individual, the level of social support that HIV-positive people receives and self-efficacy (Nel, & Kagee, 2011). Lastly they suggested that the relationship that the health care provider has with the HIV-positive patient is important in the use of ARV treatment and compliance.

A study conducted in the Western Cape focussed more on treatment support systems that patients have chosen for themselves and how this support might have an effect on medication outcomes (Nachega et al., 2010). This study looked at the primary elements of support, including the social and material resources that are needed for encouraging treatment adherence in South Africa. By way of the research questions, the barriers to antiretroviral adherence that are present for people living with HIV were also identified, one of which was the stigma associated with HIV status disclosure (Nachega et al., 2010). This study was based on social influence theories, which propose that getting the maximum benefit out of a supportive relationship may result in more

positive modes of adherence behaviour in people living with HIV (Nachega et al., 2010). In terms of stigma an increased experience of stigma may be related to a lower incidence of good quality, supportive relationships in the patient's life, which in turn may result in decreased medication adherence. Through focus groups with HIV patients and in-depth interviews with health care workers, the researchers were able to identify several key factors important in adherence. The aspect most pertinent to this research is the identification of the importance of effective treatment supporters. A treatment supporter is a person who would observe, assist and support the HIV-positive person so that he/she would not forget to take their medication consistently every day (Nachega et al., 2010). Treatment supporters are especially useful in order to sustain long term adherence, especially after the first three months of treatment where patients receive high levels of clinical support. It was reported that family members are the most likely to be chosen as treatment supporters for people living with HIV. The main kind of family support identified was financial or material and instrumental, providing transport to the clinic. Some participants also stated that family members provided moral support (Nachega et al., 2010).

The difficulty arises when people living with HIV are reluctant to disclose their status to family members for fear of stigma. According to Nachega et al (2010), disclosure of HIV status plays an important role to elicit effective treatment support for HIV-positive persons. However during the focus group, the patients conveyed a sense of reluctance toward disclosing their status. In one of the groups, four of the six participants gave the same reason for not wanting to disclose. This was fear that if family members knew their status, they would stand in the street and announce it to the neighbours. Another patient revealed that when she disclosed her status to her family members, she lost their support. She assumed that she would have financial and moral support from her family but instead her mother rejected her and turned her siblings against her (Nachega et al., 2010). Stigma related to HIV and AIDS is subsequently a significant barrier to sustaining ARV adherence and this leads to the fear of disclosing to family members who could possibly fulfil the role of treatment supporter (Nachega et al., 2010).

Another study was conducted in South Africa (in KwaZulu-Natal province) to evaluate the decision-making process that occurs for HIV testing and HIV disclosure by patients who were hospitalised with multi/extensively drug-resistant TB (Daftary et al., 2007). One of the themes that came out of the data analysis was experiences and perceptions of stigma and disclosure. The

results showed that experiences of stigma and prejudice were obvious barriers to testing and treatment. Several patients reported being scared of being seen at HIV clinics. HIV-positive people's expectation of stigma takes priority over the potential gains from treatment and this is reported to be caused by fear of being stigmatised (Daftary et al., 2007). What is interesting to note in this study is that there were more occurrences of felt stigma than enacted stigma. Felt stigma refers to the fear of being discriminated against, whereas enacted stigma is the actual experience of being discriminated against. Felt stigma compels a person to isolate themselves from others due to the fear they feel about the chance of being stigmatised (Daftary et al., 2007). There is a perceived fear of being prejudiced against and this perception in itself is enough to inhibit an individual from seeking health care. The research that has been conducted in the area of stigma is vast and constantly shows that either the fear of experiencing stigma or an actual experience of discrimination can have a major effect on an individual's treatment adherence.

2.12 Conclusion

Much of the research reviewed here suggests that women living in poverty are at a heightened risk of contracting HIV, and that the effects of HIV serve to further marginalise these women. The risks that these women face is the results of a combination of a physiological and socio-economic factors that further deprives and subordinates them. What is arguably absent, though, is the documentation of their lived experiences in their own voices, which is what this research project aims to redress.

CHAPTER 3: METHODOLOGY

As indicated in the previous chapter, this research project aims to understand the lived experiences of HIV-positive woman in poverty. This chapter describes the theoretical framework and methods of data collection and analysis that are used to achieve the research aims. Issues of validity and how these were addressed during data collection and interpretation are also discussed. Lastly, the chapter ends with a discussion of the ethical issues that were anticipated and the measures taken to minimise the risk of harm to the participants and others.

4.1 Research Framework

Interpretative phenomenological analysis (IPA) emphasises people's lived experiences, particularly experiences that are personally significant or meaningful (Smith, Flowers & Larkin, 2009). IPA is based upon three central philosophical tenets: phenomenology, hermeneutics and idiography. Phenomenology (based on the work of Husserl, Heidegger, Merleau-Ponty and Sartre) is the study of human experiences; it is concerned with the world as it is experienced by individuals in particular contexts (Willig, 2001). In IPA research participants are viewed as experts of their life experiences and, therefore, are able to provide the researcher with an understanding of their own experiences by telling their personal stories using their own words (Smith et al., 2009). According to Shinebourne (2011) "the process of phenomenological reduction involves redirecting ones phenomenological idea away from the unreflective involvement in experiences of the world towards a focus on how the object appears to consciousness" (Shinebourne, 2011, p. 17).

However, people's experiences and the meanings they derive from them are thought to be accessible only through a process of interpretation: IPA, therefore, involves a double hermeneutic whereby the researcher must make sense of the participants who are making sense of their experiences (Smith et al., 2009). Hermeneutics is the theory of interpretation, originally used as a basis to interpret religious texts (Shinebourne, 2011), and recognises that meaning is not made explicit but requires rigorous clarification (Lopez, & Willis, 2004). It is through this interpretative process that the meanings of individuals' cognitive inner worlds can be understood (Biggerstaff, & Thompson, 2008). One of the most primary aspects of hermeneutic theory is the

principle of the hermeneutic circle, which, according to Smith et al. (2009), refers to the continual interplay between parts of the text and its complete whole.

Lastly, IPA is idiographic as it aims to elucidate the detailed perceptions and understandings from a small number of individuals - ideally a relatively homogenous group of participants in order to be able to comment on convergence and divergence of experiences and meanings - without the need to generalise the findings (Conroy, 2003; Smith, & Osborn, 2003).

Interpretative phenomenology employs idiography at two levels: firstly in its depth of analysis and attention to detail, and secondly in its commitment to the subjective experiences for particular individuals in particular contexts (Smith et al., 2009).

4.2 Research Design

4.2.1 Sampling

A purposive sampling method was used for this study. Smith et al. (2009) suggest that three to six participants is a realistic sample size for a student project. As noted above, IPA specifically calls for small homogenous samples that are able to provide rich contextualised data about a particular shared experience (Smith et al., 2009). Black HIV-positive women from the Raphael Centre in Grahamstown were approached to participate in this study and six participants were recruited, which is the upper limit for a student study. The Raphael Centre is an important community initiative providing care and support to people affected by HIV and AIDS.

Inclusion criteria were that all participants should be HIV-positive women of at least 18 years of age or older, and who have been diagnosed with HIV for at least six months and supported by the Raphael Centre. A minimum of six months since diagnosis was deemed a necessary inclusion criterion as recently diagnosed people might still be in a state of shock and unable to provide the rich contextualised data that is required. In addition, proficiency in isiXhosa as well as being able to actively engage with the researcher about their experiences of living with HIV in poverty was required.

4.2.2 Data Collection

As is typical of an IPA study (Smith et al., 2009), semi-structured interviews, which are well-suited to the task of capturing people's lived experiences, were conducted. IPA requires "rich

data which is derived from participants having been granted an opportunity to tell their stories, to speak freely and reflectively, and to develop their ideas and express concerns at some length” (Smith et al., 2009, p. 56). Semi-structured interviews are guided by an interview schedule to ensure that each of the intended topic areas are covered while also allowing the researcher some flexibility to explore and pursue novel material that was not anticipated (Eatough, & Smith, 2008). In this way “the respondents can be perceived as the experiential expert on the subject and should therefore be allowed maximum opportunity to tell their own story” (Smith, & Osborn, 2003, p. 59). The interview schedule consists of 12 questions directed towards exploring the experiences of HIV-positive women living in poverty (Appendix A).

The interviews were conducted at the Raphael Centre. Interviews were conducted in isiXhosa as this is the first and usually only language of the participants and the first language of the researcher. This allowed monolingual isiXhosa participants who are especially marginalised by language, race, gender, geography and poverty to participate in research and to give their own accounts in their own words.

4.3 Data Analysis

All interviews were recorded with an audio recording device, translated and transcribed by the researcher. Transcripts were translated into English for analysis (primarily for the benefit of supervision and also to be able to disseminate the research findings). The process of analysis follows the recommendations outlined by Smith et al. (2009) and Smith and Osborne (2003), though they encourage researchers not to simply follow their guidelines in a prescribed manner but to rather allow for flexibility and creativity during the analytic process.

Smith and colleagues (Smith et al., 2009; Smith, & Osborne, 2003) describe in great detail the actual steps that are involved in an Interpretative Phenomenological analysis. Essentially the analysis involves a detailed, line-by-line examination of the first transcript to identify emerging themes, then looking for connections between these themes, then moving on to the other transcripts, and finally assembling a list of themes that cut across the cases. This is a flexible, iterative process of moving back and forth between transcripts. In writing the thesis, appropriate measures are put in place to ensure that the identities of the participants remain protected, which

include keeping the interview transcripts confidential and ensuring that the excerpts that are used to illustrate themes are anonymised.

4.4 Validity of IPA Research

As recommended by Smith et al. (2009), Yardley's (2000) criteria to assess the quality of qualitative research were used to assess this research. Yardley's first principle is that of *sensitivity to context*. In IPA methodology, sensitivity is demonstrated through focusing on the idiographic and the particular of the context. Sensitivity is essential during discussions with others when recruiting a purposive sample, liaising with participants and when conducting interviews with people who are unlikely to be comfortable talking to an outsider in a one-to-one situation. Sensitivity is also evident throughout the stages of analysis and by ensuring that any interpretative claims made are grounded in the original data; this also enables the reader to check any interpretations being made with the original data (Smith et al., 2009). In the present research, sensitivity to context is demonstrated by a review of the literature that attempts to describe the socio-cultural context of HIV/AIDS in South Africa, with a particular emphasis on the experiences of socio-economically deprived women with HIV, while the analytic claims are substantiated through verbatim extracts of the participant's experiences.

Commitment and rigour is the second principle used to assess the quality of qualitative research. In IPA, commitment refers to the researcher's ability to be attentive to the participant during data collection, and to the transcripts throughout the analysis of each case (Smith et al., 2009). The researcher is a trainee counselling psychologist and therefore able to draw upon her training and experience of attending to clients. Rigour is achieved by a thorough and systematic approach to the analysis (Smith et al., 2009). As mentioned, within the results section, each theme is supported by quotes drawn proportionately from each participant where relevant (Smith et al., 2009).

Third principle is *transparency and coherence*. An IPA researcher describes each stage of the research process in great detail in order to demonstrate transparency (Smith et al., 2009). An aspect of coherence refers to a fit between the research question and the methodology used to answer that question (Yardley, 2000). This study explores the lived experiences of HIV-positive women living in poverty, which is fully aligned with the research methodology.

Lastly, the fourth principle of *impact and importance* focuses on the significance and usefulness of a qualitative research project. The real validity of a research project is whether it has something important, interesting or valuable to say (Yardly, 2000). The voices of marginalised women such as the participants of this study are absent in much of the HIV literature, as so many studies rely on quantitative analyses while even qualitative studies often recruit bilingual rather than monolingual women, who perhaps represent a more empowered group of women than those who cannot speak English or Afrikaans. Thus the impact of this study is enhanced by giving voice to women who are in many respects voiceless.

4.5 Ethical Considerations

According to the American Psychological Association, the examinations of the human condition should be used to promote human welfare (Kvale, 2007), which implies that such research should be conducted ethically. Ethical considerations are particularly important to qualitative research as the process of in-depth interviewing involves the illumination of an individual's private life in the public domain. The researcher is therefore responsible for ensuring that the process is conducted with respect for the participant's well-being. The process of ensuring strict ethical practices began prior to data collection, throughout the data collection process, during data analysis and in the final write-up of the findings (Smith et al., 2009).

A number of possible ethical issues were anticipated, some that are general to all human research and others that are specific to this type of research: Questions regarding diagnosis and the experiences of treatment were thought to have the potential to cause some level of distress, and therefore debriefing sessions were provided to participants after the interview process. Again, that the researcher who conducted the interviews is a trainee counselling psychologist is a factor that mitigates this concern. Additionally, a concern for the psychological support for participants is a primary motive behind the decision to approach participants who are actively involved in a supportive organisation rather than recruiting them in a public domain. While always sensitive to issues of vulnerability and while acknowledging that these women are particularly disempowered due to their HIV status, race, gender and socio-economic status, the researcher, however, remained mindful that they are also resilient adults who have endured multiple challenges and should be treated as such.

Before the Raphael Centre or its clients were approached, ethical approval was obtained from the Rhodes University Psychology Department's Research Proposal and Ethical Review Committee (RPERC). Once this was obtained, permission was sought from the Director of the Raphael Centre to approach potential participants (Appendix C). Following the permission of the Director, the clients who use the support group were addressed and were provided with information regarding the topic of the research project, the possible benefits and risks pertaining to participation, and their rights as research participants. These rights are articulated in the consent form (Appendix B), and emphasise the voluntary nature of participation, individual participant's right to decide what to disclose during the interview process, and their right to withdraw from participation from the study without incurring any negative consequences. Potential participants were also notified their consent would be required from each participant to record their interviews with a digital recording instrument (Appendix D). It was further explained that the interview transcripts would be kept confidential and that pseudonyms would be used throughout the written thesis. Potential participants were also invited to raise any concerns and or questions before agreeing and starting the interview process. Finally, signed consent forms were obtained prior to the interviews.

4.6 Conclusion

The aim of the research, which is to explore the lived experiences of a small sample of HIV-positive women who live in poverty in Grahamstown in the Eastern Cape, was achieved by interviewing such women and analysing the interview transcripts from the perspective and by using the methods offered by Interpretative Phenomenological Analysis. Ethical considerations pertinent to the research are anticipated and addressed. The findings of this analytic effort are described in the following chapter.

CHAPTER 4: FINDINGS AND DISCUSSIONS

4.1 Participants

Black HIV-positive women attending support groups at the Raphael Centre, a local NGO that provides support to HIV-positive individuals around the Grahamstown community were approached. Six participants were recruited to take part in the study. All six participants were HIV-positive; they were all Xhosa speakers and have known about their positive status for more than six months prior to the interview process. To assure that their anonymity is preserved, each of the six was assigned a pseudonym.

4.2 Findings

A number of themes relevant to the aims of the research project were identified. Many of the themes overlap but will be discussed separately. The first theme that was identified is that of *experiences of diagnosis*. The theme of diagnosis refers to participants' reactions after receiving an HIV-positive diagnosis. Testing for HIV, understandably, provokes a great deal of anxiety because many people still view HIV as a catastrophic and 'deadly' disease. While the second theme of *disclosure* refers to women's decision to reveal or not to reveal their HIV-positive status to others. Both themes were present in every story and thus a significant part of each woman's experience of living with HIV. The third theme is that of *stigma*, which can be both internal and external. Stigma can represent fears associated with HIV such as fear of rejection, isolation, societal judgements and prejudice. The fourth theme is *ARV experiences*. This theme highlights some of the challenges these women experienced and the meaning that is attached to antiretroviral treatment. The fifth theme is about *social support*. The sixth and final theme is that of the women's experiences of living in *poverty* and describes the challenges they are faced with on a day to day basis and how they manage these challenges while living with HIV.

4.3 Discussion

4.3.1 Theme 1: Experiences of Diagnosis

4.3.1.1 Reasons for obtaining an HIV test

Many people do not voluntarily have an HIV test without a reason to do so. Steinberg (2008) reports that people typically do not get tested until they are very ill because of a fear of stigma. Similarly, Gilbert and Walker (2010) reported that people avoided getting tested because of the fear of an HIV-positive diagnosis; therefore testing was almost like a ‘forced’ health related act.

As Zethu mentioned in her transcript below, she had an HIV test because she suspected that she might be HIV-positive as a result of the physical symptoms she was experiencing at the time.

“Yes we didn’t use condoms. People would advise me to leave this guy but I didn’t listen. Then I started having these funny things like skin rash and those things on my mouth (pause) mouth sores and I had a crush on my tongue. I then thought I have never had these kinds of things before, so I decided to go to the clinic then. That’s when I went to Mama Sam and told her that I wanted to go to the clinic and get tested. She asked me ‘to test for what’. I told her that I wanted to do an HIV blood test. She asked me if I was ready and told me that a person who wants to get tested for HIV has to be ready and must be sure that they want to know their status. She told me that she didn’t want to take me to the clinic if I was not ready because hearing that you are HIV positive can be shocking. I told her I was ready, I just want to know and I will accept my results whether positive or negative. So Sam then asked one of the teachers at Khululani to accompany me to the clinic” (Zethu).

Like Zethu, both Lutho and Zintle indicate that their HIV tests and diagnoses were prompted by the occurrence of physical symptoms:

“I found out about my status after I had my baby girl but she is not HIV-positive. I got it from my first boyfriend. He went away to Cape Town to find a job and then when he came back we got back together. All along he knew he was HIV-positive. I was never promiscuous, from an early

age I was always in doors you know. I then realised that I was starting to lose weight but I was not sick or in any kind of pain, I went to the clinic and got tested and the results came back positive” (Lutho).

“My right knee got twisted in such a weird way and was so painful hey. I went to this lady who was a herbalist in my location in JHB. She gave me some traditional herbs to drink and ointment to rub my knee with. She really helped me and my knee went back to its normal form. I got sick and then went to hospital and it was found that I had meningitis and then I asked them to transfer me to the Eastern Cape so that I could get my treatment this side since I knew I was going to come back home. I came back home and then went to the hospital here. It was TB meningitis so then because I was really sick they sent me to Themba hospital. So in JHB I had already got tested for HIV as well so when I got here I knew already. I then started treatment this side. My CD4 count was low so asked to start treatment” (Zintle).

It was not long ago reported that HIV infected individuals avoid HIV testing because there is no cure for the disease should their results reveal infection (Peltzer, 2003). However, since then the national rollout of ARV treatment has changed what was once a very bleak outlook to one where most HIV-positive can hope for a normal lifespan. This might explain why there is no evidence of the supposed fear and avoidance of testing amongst these participants. One could also speculate that given the adversity that these women face on a daily basis, a diagnosis of HIV-diagnosis is just another of many misfortunes. Having a positive attitude to the testing and believing that it was not the end of the world seems to have encouraged most of these women to get tested.

4.3.1.2 Knowing versus not knowing

For some of these women having an HIV test meant a great deal to them regardless of their positive results. According to some of the participants, knowing one’s status meant that the HIV-positive individuals were ‘better’ than those who did not know their status and it seemed to create a sense of ‘us vs them’. The participants seem able to take some comfort in knowing their status and being able to focus on maintaining their health.

“On my side I’d say it’s nice, because firstly I know that I am HIV-positive, so to me knowing your status is better than not knowing. When you don’t know your status you think about a lot of things like what will happen when I found out, what will I do? Some people think that they will never have HIV, those people struggle when they are told that they are HIV-positive; they don’t want to accept it. Because some people tell themselves that they will never be HIV-positive so then they end up killing themselves when they find out. I am now happy because I know where I stand in life. There’s only one thing I am faced with now and that is my health” (Zethu).

4.3.1.3 Reactions to the positive diagnosis

Yet while the participants seem to have had a positive approach to testing and to their status, this does not mean that it was not very distressing to receive their diagnoses. Receiving an HIV diagnosis evokes strong feelings for most people. All the women described their personal experiences of receiving an HIV-positive diagnosis, and they all seem to have had similar emotional reactions to the results. Receiving an HIV-positive status can be life threatening, so much so that people almost wish they had not had the test. Some participants report that they were shocked after receiving the diagnosis, while others report denial and disbelief about their HIV-positive diagnosis.

“I didn’t get shocked but I felt numb and lost because I didn’t understand anything being said. The teacher who was accompanying me started to cry and the nurse as well, only then my senses came back and I realised that it was true, I was positive” (Zethu).

“For a second I couldn’t believe that it was true because I was very shocked you know, but then because I knew I had unprotected sex (pause) so I knew it was possibly true. But part of me wished it wasn’t true you see” (Nandi).

For some, the immediate response is to think about death. According to Simon (1979) that person will also be grieving and mourning some loss, which can be loss of life associated with anticipation of death, or loss of time as a result of a now limited life span. Zintle described her

experience of witnessing other people, who were ill because of HIV, die and how that made worse her feelings of fear of dying.

“I was scared that’s why I was stressing. I was really scared of dying and that was made worse by seeing people die next to me. I remember the other time when another person was dying next to me and I was crying and calling nurses but no one responding. Sometimes nurses will just leave and not care” (Zintle).

Denial is characterised by the refusal to believe what has happened. At this point the individual might insist that the HIV diagnosis is incorrect and may try to seek verification from other institutions (Tilley, 1990). Some of the participants in this study reported having asked for a test to be done more than twice to verify their results as they did not believe they were accurate.

“Yhoo! I was shocked and in disbelief about this, the nurse said she will do another test to confirm the first results and it was positive again, I couldn’t believe it you know” (Busi).

Some individual are said to feel numb, blank, experience panic attacks, and an inability to express themselves, while at times they might have disorderly thoughts (Tilley, 1990).

“I think I was numb and still in shock. I asked the doctor if he was sure that I was positive and he said yes but he told me that he will do another test and that was positive too. He then said I must come back after 3 months, I went back after 3 months and again results were still positive. I struggled to believe it because I was hoping that the results would be different this time around you know” (Zintle).

Westbrooke and Viney (1982) stated that anger, as a psychological reaction to the onset of chronic illness, is often generated by feelings of frustration associated with the illness. Anger seems to be mainly directed at the people who were thought to be responsible for infecting them. Simon (1979) views anger as an integral part of the grieving process. Lutho reported being angry at her ex-boyfriend because he was the one who infected her with HIV.

“I was angry and shocked and I couldn’t believe it at all, I thought I was dreaming or something you know. I couldn’t believe that it was me who was HIV-positive because I had told myself that I will never be positive. I was not very educated about HIV so because I knew I was not sleeping around with many men I was safe” (Lutho).

The emotional reactions also includes feelings of self-blame and guilt at being infected. This reaction is caused by the perception that women who are infected with HIV are promiscuous (Bennett, 1990).

“I knew what I was doing so I accepted it. I did not protect myself by using a condom so it was my fault you see” (Nandi).

Some women reacted by passively accepting their HIV status. They seem to have easily accepted their positive diagnosis; this could be a result of the helplessness that one feels when diagnosed with a chronic illness that is incurable. It could also be due to the fact that they were aware of the possibility of being infected, either from knowing that they were involved in risky sexual behaviours or from their partner’s promiscuous behaviour.

4.3.1.4 HIV Diagnosis and adjustment

The patients who adjust best are those who become positively preoccupied with their HIV-positive diagnosis. They are said to develop an altruistic commitment to assist other people living with HIV. An attitude of acceptance implies that whatever the stage of infection, the person is able to act rationally, feel in control and is able to accept the best help that is available, and is able to maintain and develop responsibilities in relationships, and make appropriate plans for the present and the future (Tilley, 1990).

“Since I found out about my status I accepted myself and then decided that I will not hide or be secretive about my status. I tell everyone I know about it; it’s only a few who don’t know about me being HIV-positive. I tell anyone and I tell them that I was not raped or promiscuous, it came to me. The only challenge was to accept myself after that; I don’t have any challenges. If you get

knowledge about your treatment and know what you have to do. I saw on the TV how people live longer with HIV and asked myself if they can live longer so can I, it doesn't matter if I don't have a lot of money but I can still live longer as well" (Lutho).

4.3.2 Theme 2: Disclosure Experiences

4.3.2.1 Positive and negative effects of disclosure

The process of disclosing HIV status differs from one person to another. It involves deciding about how, when, to whom, under what conditions to inform others of one's HIV status. Some people choose to disclose their status soon after receiving HIV test results, others disclose after days and weeks, some take years to disclose, while some decide to never disclose their status to anyone, fearing the consequences if their status became widely known (Haricharan, 2010).

"I then thought who I would tell because my mother is an alcoholic and doesn't really care; me and my sister don't get along since the Johannesburg thing happened because when I told her about what her boyfriend almost did to me she didn't believe me. She said I was lying and causing trouble for her and her boyfriend. So I decided not to tell anyone about my status. I kept it to myself and I just kept going to the clinic. I never told my family" (Nandi).

Because disclosure is a pre-condition of social support and HIV treatment, people are encouraged to share their HIV status with others, especially their families and friends. Yet due to the stigma and discrimination associated with HIV, deciding whether or who to tell is a dilemma, as it is often impossible to judge how people are going to react (Haricharan, 2010). According to the findings of this study it appeared that disclosure brought mixed feelings for most of the women. All of the women attended a support group and reported that they are encouraged to disclose their status as this is considered to be empowering. However, it appears that little emphasis is given to the possible negative outcomes of disclosure in the support group and that many HIV-positive people are not well equipped to deal with the negative effects like discrimination and violence after disclosing their status.

In particular, some of the women reported that they felt helpless when their families were not supportive after they had disclosed their HIV-positive status. It is often assumed that families will be supportive and accepting after one's status has been disclosed (Haricharan, 2010), but in this study the findings illustrate the opposite. Some people do not trust their family members as much they do trust their close friends and therefore prefer to disclose to their friends rather than their family members. For some women non-disclosure or being secretive seemed to provide a sense of relief for them because they did not have to face the stigma and discrimination they expected from others. Instead they were able to select a few individuals to disclose to. Although, according to numerous studies, non-disclosure appears to have many negative effects on the person's life (Haricharan, 2010).

For Busi, the dilemma of risking stigma for social support was resolved by a partial disclosure by restricting the knowledge of her status to her grandmother only:

"I thought to myself the only person I trust and I could possibly tell was my grandmother, so I just went straight to her house and told her everything. Because other people in my family are not right, I knew they would insult me and use my status against me. So I only told my grandmother and I just carried on as normal" (Busi).

Zethu, on the other hand, did not have a positive experience of disclosure:

"Then I tried to accept myself but what I found out in the process of accepting myself, I did not get support from my own family because when I told my family about my status and it became a big thing to them. I found that they were discriminating against me; I even had to move out of home because I could not be around people treating me so bad you know? " (Zethu).

Zintle's family was similarly unsupportive:

"I told my family about my status and it was like I had given them a reason to be mean or something to use against me when they needed to. Now people when they were drunk would

insult me and call me all names you see. I wish I had not told them because I couldn't even argue with them because what they were saying was true, I am HIV-positive, so ja. I know I should stand up for myself but what do you say when your own family insult you?" (Zintle).

The theme of disclosure, referring to the decision to tell or not tell as well as to whom one should disclose, appeared to reflect participants' coping mechanisms. Disclosure seemed to be a validation to some of the women that they had truly accepted their positive status and that they were not ashamed of it. Levy et al. (1999) cited disclosure as a measure of people's acceptance of their diagnosis. The results of this study found that all their participants did disclose to someone and it did seem to reflect a level of acceptance, even though many women were very selective of whom they disclosed to. This could be because most women were stigmatised not only by community members but by their own family members as well. Levy et al. (1999) also found that disclosure was a way of releasing tension. This study found that disclosure goes beyond just fulfilling the need of releasing tension, as people disclosed their status in order to fulfil emotional, financial and medical needs too.

Disclosure is said to be associated with increased social support, acceptance and kindness, decreased anxiety and strengthening of relationships (Haricharan, 2010). This, however, is not always the case as some of the women in this study indicated that they experienced rejection and discrimination after disclosing their status. Therefore, we can assume that the context in which an individual decides to disclose is important, such as family context and must be chosen with careful consideration of both positive and negative consequences of disclosure at a personal level. In the literature there seems to be a great deal of evidence for the negative effects of non-disclosure or rather limited disclosure (Levy et al., 1999). However the results of this study show that non-disclosure or partial-disclosure is not entirely negative. In fact for some women non-disclosure or rather very limited disclosure appeared to be a way of coping with the virus and avoiding a negative outcome. By keeping it a secret to others they seemed to find some way to fight the virus and remain positive. Non-disclosure or partial disclosure provided comfort for some as they did not have to fight stigma and discrimination; instead they could get well independently and return to the world 'untarnished'. Although some women might have chosen not to disclose their status to other people, because they were part of an HIV support group, their

HIV-positive status was inadvertently disclosed to the community, putting them at risk of stigma and discrimination. Certainly one reason to encourage disclosure is that the inadvertent disclosure of HIV status is hard to avoid.

“Ahm, when I think about it, I think because we are being transported to and from the support group by the Raphael centre’s bus; so I think people who see us in the bus think ‘they obviously have HIV and are sick’. I think even if a guy liked me if they saw me in the bus they would stop liking me because they will know I am HIV-positive obviously because I go to the Raphael centre. I don’t even have to tell people that I am HIV-positive because it is obvious when you go to a support group. Some people say bad things but I don’t really pay attention to those things. I know that people judge us when they see us in that bus” (Nandi).

Concealment of an HIV-positive status might reduce the risk of revealing a stigmatised identity, yet such strategies limit discussions around lived experiences and the sharing of emotional difficulties experienced by HIV-positive people (Norman, Chopra, & Kadiyala, 2007). Women who got infected with HIV as a result of rape may choose to not disclose their status as way of protecting themselves from having to disclose the rape as well.

“I know that there are a lot of things that people think. For example I am sure that there are people who think about the fact that I was once a tomboy and then I went to JHB but I came back pregnant and HIV-positive. So they probably think that I was promiscuous in JHB and maybe that’s how I got to be HIV-positive. I mean most of the time HIV is associated with having multiple partners you know, but they don’t know that I was raped and that is how I became HIV-positive and some people don’t really know about my positive status they just assume you know” (Akhona).

The decision whether or not to disclose is also influenced by the socially constructed beliefs surrounding a positive status. In most South African communities, HIV transmission is regarded as a consequence of an immoral act which discourages HIV-positive individuals from disclosing their status. Disclosure of an HIV-positive status often results in isolation, prejudice, termination of relationships, verbal and physical abuse, and violence (Gilbert & Walker, 2010). Religious

teachings, which state that HIV and AIDS are punishment from God, make people feel guilty, hence less likely to disclose their status for fear of being blamed of unfaithfulness and adultery. This is in line with the findings of this study as most of these women experienced stigma after they had disclosed to their families and friends. Some women used public disclosure as a way of coping with the virus; this is evident in what Lutho reported below. Furthermore, public disclosure seemed to foster good relations with others as well as provide numerous opportunities for support. These findings correlate with those reported by Paxton (2002).

“Since I found out about my status I accepted myself and then decided that I will not hide or be secretive about my status. I tell everyone I know about it; it’s only a few who don’t know about me being HIV-positive. I tell anyone and I tell them that I was not raped or promiscuous, it came to me. I was always in the house well behaved you see and my ex-boyfriend infected me with HIV. People like to say that ‘maybe she had a lot of men that is why she is sick now’ you know, it’s not like that” (Lutho).

Yet even these attempts to address people’s stigmatising assumptions do not necessarily result in acceptance, as Lutho indicates below.

“Most of the time we are not accepted in churches, mainly because HIV is seen as taboo in most churches” (Lutho).

Indeed, stigma is seems to be an unavoidable feature of living with HIV.

4.3.2.2 Disclosure and intimate relationships

Disclosure to a spouse or sex partner(s) is very important, particularly for preventing HIV transmission. Haricharan (2010) is of the opinion that disclosure to sexual partners needs to be facilitated, as many hesitate to do so due to fear of being rejected; this leads to further unprotected sex and increased risk HIV infection. Yet, women are reported to be at risk of violence following disclosure of a positive status because women are often blamed for bringing the HIV to the relationship (Leclerc-Madlala, 2001). It is reported that fear of rejection and abuse

can also lead to non-disclosure (Leclerc-Madlala, 2001). This is evident in what Akhona and Zikhona reported below.

“The first challenge I think of is that of deciding whether to disclose to your partner or not. I have never been truthful to someone I am dating about my status because I don’t want him to use my status against me. I have seen guys insulting their girls about their HIV-positive statuses once the relationship has ended, I don’t want that. Also I am scared that maybe the guy will then leave me because of fearing that I will infect him, but I always use a condom with a guy I am dating always. People also say hurtful things also like ‘dead person walking’ those are the things I choose to not say anything. I don’t disclose to protect myself and I am doing just fine” (Akhona).

“As a woman I would say it is challenging when you have a boyfriend because it is difficult to disclose your status, you know! Especially when you love someone maybe after disclosing he dumps you. But then again if you are an open person like I am you would want to disclose and if that person really loves you they will accept you. To me how a person reacts is up to them but as long as I have told them the honest truth and they know. They must know so that they don’t think I was tricking them or something. Sometimes a guy would come to you and claim to love you and then you have sex without a condom with them, when you find out that you are positive he will put the blame on you. So I think it’s safe to disclose before the relationship goes any further. But other people don’t disclose on purpose because they want to spread the disease even though they know it’s wrong and it’s risky. This then cause complications for the positive person because their immune system becomes weaker. So those are the kind of challenges we are faced with. Also the fact that people are always gossiping about you and stigmatising you” (Zikhona).

According to Jarman, Walsh, and De Lacey (2005) women in relationships where their HIV status is known are reported to have fewer experiences of anxiety concerning psychological protection of the self. Yet the relationship between disclosure and psychological safety is complex given that disclosure is a precondition of both support and rejection.

4.3.3 Theme 3: Stigma

Deacon et al. (2009) suggests that stigma is essentially an emotional response to danger that helps people feel safer by blaming others to distance themselves from risk. Stigmatisation consequently creates comfort, a sense of control and immunity from danger at an individual and at a group level. Stigma, to a large extent, seems to inform people's strategies for survival. Most of the women expressed a fear of stigma based on their actual, first-hand experiences of it. These findings appear to be consistent with the literature.

Deacon et al. (2009) found that stigma seems to change the way in which people see themselves. What is interesting to note in this study is that there were more occurrences of enacted stigma than felt stigma. Felt stigma is said to be stigma which has been internalised by people who have experienced stigma and have accepted the negative judgments made about them as truthful. While enacted stigma is referred to as the actual experience of stigma and discrimination (Deacon et al., 2009). Below is an illustration of what Zethu reported about her personal experiences of stigma.

"I have experienced that a lot; a lot of times in my area people will treat you like you are a dog you know and will say mean things about you behind your back. I just go to them and tell them yes it is true I am positive because it makes me angry when they keep gossiping behind my back. I sometimes just give up and think about that verse in the bible that says "God forgive them for they don't know what they are doing", they don't know why they gossiping so I just forgive them. I think they want you to hate yourself and not have good relationships with others and be a loner. They just want to make life difficult for us people living with HIV. But if you are strong they will end up giving up on that. They end up coming to you after they have seen that their gossiping doesn't affect you, they come to you and want to be friends now asking for forgiveness" (Zethu).

Stigma is a social process that represents the voice of society. Stigma seems to disempower HIV-positive people in that they feel the need to keep their illness a secret and would often shoulder the burden alone, rather than share their diagnosis (Herek & Glunt, 1988). As mentioned above,

some of the women because of extreme fear of stigma choose to disclose their status very selectively; this selectivity was brought about by experiences with their families. Akhona was one of those who decided not to disclose to their families.

“Yes I will not disclose because I am protecting myself from people insulting me or treating me bad because of my status but I will always be responsible and use a condom all the time” (Akhona).

Deacon et al. (2009) suggested that one of the reasons for stigma is people’s fear of contracting HIV and that often this fear is exacerbated by misconceptions about transmission.

“When I disclosed initially to my family they were not accepting, especially the extended family. I could see they were scared of me somehow. I remember my other cousin when I visited their house she would not want to use the same things as me like a mug or plate. I had my separate mug and plate when we went there. They also would spread rumours about how I got to be ‘sick’ that I was sleeping around in Johannesburg. They only changed after I had spoken up to them and told them that what they were doing was hurting me” (Zintle).

Zintle was under the impression that she would have moral support from her family but instead they rejected her and discriminated against her. The rejection by her family deprives her of potentially very helpful treatment supporters (Nachega et al., 2010).

Stigma can be encountered in all areas of existence, including employment as Zethu verified below.

“You just have to keep trying to look for the job, but there are jobs where people who are HIV are discriminated against and then they end up not getting the job. You see I know a friend of mine who is also HIV-positive; she was working as a cleaner at the university but because she had to fetch her treatment she had to ask to her manager and her manager wanted to know why

she needed day offs a lot but she didn't want to tell her that she was HIV-positive because she was scared what if she lost her job and scared of being discriminated against” (Zethu).

HIV and AIDS-related stigma is generated and expressed in different symbolic, economic, political and institutional contexts (Deacon et al., 2009). People may stigmatise friends and family differently (Deacon et al., 2009). It has been confirmed in South Africa that stigma across contexts shares many common features. For instance, in the context of the heterosexual epidemic, HIV infection is commonly associated in a shaming and blaming discourse with sex and specifically with promiscuity. As illustrated below by what one of the participants reported, women living with HIV are assumed to be ‘promiscuous’ or ‘immoral” (Deacon et al., 2009). Essentially AIDS is seen as a consequence of what is commonly perceived as deviant and immoral behaviour. Due to these reactions HIV-positive people, women in particular, are often blamed, feared and shunned as opposed to receiving compassion and assistance (Deacon et al., 2009).

“I tell anyone and I tell them that I was not raped or promiscuous, it came to me. I was always in the house well behaved you see and my ex-boyfriend infected me with HIV. People like to say that ‘maybe she had a lot of men that is why she is sick now’ you know, it’s not like that.” (Lutho).

Additionally, the association between HIV/AIDS and death is a source of stigma. *“What can I say? Some people think that because you are positive you are going to die soon. So you as a positive person you can't have a headache without people thinking it's a sign of death or you can't have a cough or something like that. People await you being sick, it's even worse if you have side effects because people think there's no hope for you. I don't bother myself about what other people think, they can think whatever I don't care really because they will never come to you and say it. I know that some people think that I will get sick and die but it's funny to me because someone who is not HIV-positive can die anytime and leave behind the positive person, that's how life is. As long as I have accepted my status and live a healthy life I consider myself like everyone else, what the other person thinks is not my business” (Zethu).*

4.3.3.1 Coping with stigma

Some women were better able to cope with the stigma than others and tried to not let it have a huge effect on their lives. What seemed to also help some of these women in coping with stigma was the fact that they were attending a support group where they were getting equipped with knowledge and support on how to respond to stigma. Below Zethu illustrates how she coped with the stigma that she was experiencing.

“So I then acquired a lot of knowledge around HIV and now I can stand up for myself even if someone is talking on the streets about me, stigmatising or insulting me about my status, I am now able to answer them and I can now handle situations like that. I didn’t know what to do and I was starting to blame myself about this HIV but when I got help here at Raphael centre, I then realised blaming myself was no use because I already had the virus and I just had to accept it” (Zethu).

The fear is not only about stigma that is directed to the self, but also stigma that could be directed at their children. It appeared that having HIV as a parent was ‘shameful’ enough and the thought of having a child who was HIV-positive was even more ‘shameful’.

“As woman you also think about pregnancy, when you are pregnant you are always worried. Even though you will be taking treatment to prevent passing this disease to your baby, it is possible that the child might get infected. So you are in constant worry because you are hoping that the baby won’t be infected and end up being positive like you are. It’s fine if I have it but not my child as well No! I don’t want my child being treated bad because of me. So that is really worrying” (Zethu).

“Because I was always worried about passing the virus to her, yho! I was just worried shame. Yhoo! A child and her mother both HIV-positive that’s a shame, I couldn’t deal with that” (Busi). Lutho suggests that her self-stigma was based on the thought that she could have infected her child.

“Yes I worry a lot, it’s like I need to make sure that whatever makes her sick is not HIV. I don’t trust anything because I sometimes think if she were to be HIV because she is young she could die and I could lose my only child. At some point I was resentful of myself when thinking about the possibility of me infecting her” (Lutho).

4.3.4 Theme 4: ARV experiences

4.3.4.1 ARV side-effects and adherence

Antiretroviral medication adherence refers to taking medication on schedule in the right doses and in the right way (Jones, 2005). Furthermore, HIV treatment adherence means a minimum of 95% compliance with prescribed doses each day. The main purpose of antiretroviral treatment is to suppress the lifecycle of the virus to maintain the health of HIV infected people (Jones 2005). However, ARVs often involve serious side-effects and other difficulties involved in taking medication. Common side-effects include headaches, tiredness, insomnia, dizziness or stomach aches, most of which are reported to go away within two weeks or three months of commencing treatment. Women are more prone to severe side-effects and toxic manifestations than men (Squires, 2003). Most of the women in this study reported having stopped their medication impulsively because of the side effects they were experiencing. Because ARV side effects can be noticeable physically, it is evident that HIV-positive people by taking ARVs run the risk of being identified as such by others, which could cause feelings of shame and lead to stigmatisation, possibly resulting in non-adherence. The challenge of dealing with side effects is illustrated below by Zethu, Nandi and Zintle’s transcripts.

“The difficulty is the side effects, because, yho! The side effects are not nice. Sometimes you take your treatment without anyone noticing or knowing that you are sick, and then the side effects can show that you are sick. For example there different types of ARVs like the one that is called D4t that one made me shapeless and can also give you lumps but it was stopped because it had really bad side effects on me” (Zethu).

The major side effects become problematic in the treatment of HIV as they sometimes lead to physical distortion and major discomfort, sometimes to the extent that people stop their treatment (Jones, 2005).

It is not always the side-effects, though, that can cause people to discontinue their medication, as Akhona describes below.

“Yes I didn’t experience any side effects when I started taking them. What happened was that I started having these sores on my mouth and a body rash that’s when I started taking the treatment but then I got better and I just stopped taking it. When I stopped the sore and rash came back again so then I realised that I should not stop taking my treatment because it helps me by keeping me healthy but it was making me feel bad” (Akhona).

From the findings of this study lack of knowledge about how ARV medication works was one of the main causes of non-adherence to ARV treatment. Some of the women were not sure whether some of the physical changes they were experiencing were side effects or not. This could be a result of lack of psycho-education around ARV treatment from government clinics or hospitals which then lead to non-adherence of ARV treatment. Sometimes the fear is that the physical side-effects will give people’s HIV status away.

“I didn’t have any challenges with it because I didn’t have any side effects except that when I started taking the treatment my body started to look different, my body shape changed. I used to have nice curves you know (laughs) but now I don’t have much of them left. I noticed that my breast become bigger and I used to have small breast. It’s embarrassing though because people ask you haybo! What happened to you now and what do you say because you don’t want everyone knowing that you are HIV-positive you see” (Zintle).

HIV-positive patients should be informed about the ARV side effects and how to manage them to help enhance ARV adherence. Knowledge of how one’s medication works is reported to be a precondition for adherence. It is reported that knowledge may also promote the development of

adherence skill and may result in increased motivation. A person who makes the effort to learn about an illness is said to make the effort to control it (Gilbert, & Walker, 2010). Some of the participants reported that once they started coming to the Raphael centre for the support group, only then did they have a better understanding of their treatment and how it works and why they had to take it.

“I think at that time what made it difficult for me to keep taking my pills was because I didn’t have support. At the clinic also it was not explained properly to me how the treatment works you see. So being here at Raphael centre helps because we would have sessions on how treatment works. It was explained what each pill I took did and why I needed to take them. So it helped because I don’t just drink my pills now I understand how they work and why I must take them. Especially if you want to live you will take your medication properly” (Zethu).

It appears that experiencing side-effects is also associated with being ‘dirty’ and that one’s body is rejecting the ARVs when one experiences side effects; this is evident in one of the women’s transcript below:

P: “I did not experience any side effects when I started taking my treatment. My body was clean” (Lutho).

I: What do you mean when you say your body was clean?

P: “I was not sick I was healthy taking my treatment with no problems. My body was not rejecting the ARVs you see” (Lutho).

This therefore suggests that side-effects are stigmatised as being the result of an unclean body. One can assume that if that is the perception held about ARVs in most communities, many people would then have negative attitudes towards taking ARV treatment that could possibly lead to high rates of non-adherence. Because side effects are different from person to person,

people often struggle to understand the cause of this difference and this usually results in people having false beliefs similar to Lutho's

Zintle suggests that it is very easy at first to forget about the pills, but not anymore.

"Yes I used to forget at first when I had just started taking the medication but not anymore. You see the thing is you have to remember to take them at the same time and it's easy to just forget about them" (Zintle).

4.3.4.2 Alcohol use and ARV treatment

Alcohol is a factor in the non-adherence of ARV treatment, primarily because alcohol use interferes with people's ability to remember to take their medication at specific times (Kalichman et al., 2009). In fact, even low levels of alcohol use are commonly associated with non-adherence to treatment, including drinking quantities beneath an individual's threshold for intoxication (Kalichman et al., 2009). It is also reported that HIV-positive people believe that mixing alcohol and ARVs would make their treatment ineffective, that mixing the two is toxic, and that mixing could make HIV worse (Kalichman et al., 2009). Not surprisingly then, some of the women in this study reported that it was not the 'right' thing to drink alcohol while taking ARVs. One of the women reported that alcohol was the reason she defaulted on treatment.

Yet abstaining from alcohol is a challenge, even for those who recognise that alcohol usage might detract from the effectiveness of their HIV treatment. The findings reveal that these women are faced with the dilemma of not wanting to compromise their treatment whilst not wanting to isolate themselves from other women who are HIV negative (or unaware of their status), who can have fun and not worry about taking treatment. This is a struggle especially for young women who want to enjoy their youth and living in a South African context where alcohol is the 'norm' for having fun (Schneider, Neuman, Chersich, & Parry, 2011). Similarly, because treatment supporters are usually people from the same community or related to the HIV-positive individual, they might also have similar problems causing them to drink and forget that they have to remind others to take their treatment.

“Yho! When you are taking medication, what can I say, sometimes it’s okay and sometimes it’s difficult. Because when you are taking medication there are things you shouldn’t do, things that don’t mix with your medication. Like you cannot drink alcohol you see and take medication at the same time because that is dangerous. You must know and always remember the time when you take your treatment by. I take my pills at eight at night and I must remember to take them at the same time every day. I have those that I take in the morning and evening at the same time and then there are those I take at night only. It’s difficult to remember you see the time every day. When you are taking ARVs like me you see whatever you do, you must do it knowing that you are HIV-positive but don’t give yourself that when you are around other people. Like just because you are HIV-positive doesn’t mean you cannot do things that negative people do, but you must do it knowing that you yourself are sick therefore cannot compare yourself with people who are negative, but that does not mean you must make it obvious to other people. For example when I am with my friends, as young people we like fun, you know! So just because someone is HIV-positive does not mean you cannot drink alcohol and have fun but you must just monitor your drinking very carefully. You can’t drink like the negative people do. One must think for themselves that they must still take their treatment and remember that the treatment you are taking does not mix with alcohol. So to make sure that I live a long life, I must help the treatment so that it can help me” (Zethu).

While Zethu seems to have found a safe balance, Nandi’s experiences, in contrast, highlight the danger of drinking excessively:

“What made me default my treatment was nothing else really besides alcohol, because I drank a lot and then I would forget to take my pills” (Nandi).

I: Was your supporter not meant to remind you about your treatment?

Participant: “My supporter was drinking with me as well so we would both forget about me having to take treatment. And besides I can’t expect someone who has their own worries to always remind me about my treatment it’s my problem” (Nandi).

4.3.5 Theme 5: Experiences of social support

Socially isolated individuals who suffer from a lack of support within their social environment are more vulnerable to all kinds of mental illnesses, especially depression, and the vulnerability to mental illnesses seems to be associated with a premature death (Nachega et al, 2010). Social support can be obtained from family, friends, co-workers, spiritual advisors, health care personnel, NGO personnel, and members of one's community or neighbourhood. Most of the women in this study receive only a little social support from their families; Most of the support they relied on came from their support group.

4.3.5.1 Family and friends

In a study conducted by Lichtenstein, Lska, and Clair (2002) women more than men are reported to experience social isolation or rejection from families and friends after disclosing their HIV-positive status. This could be a result of the stereotype that women who are HIV-positive “deserve to be positive” as they are perceived as “promiscuous”, and often receive no empathy from family, friends and the community (Leclerc-Madlala, 2001). Also women who lack social support experience more distress than men and are more likely to be depressed as a result of this isolation. However regardless of what is reported by Litchtenstein et al. (2002), a number of studies together with the findings of this study show that women more than man are more socially resourceful and will explore different ways in which they can find support to help them deal with their HIV-positive status (Jewkes, 2009).

“It is nice to get support; I got support from my child and my best friend. I have a friend that I have been friends with since childhood. She accepted me when I told her about my status she loved me and never changed. But my family yhooh! They just abandoned me and never came to visit or even check up on me when I was sick. It’s not nice to not have your family support you. Being rejected by my family and not getting any support is difficult. That is why some people decide not to disclose because people will stigmatise you and insult you about your status when they are drunk, it used to happen to me also” (Lutho).

The social support that participants receive might serve to counteract their own internalised stigma (Young, 2011). Being accepted and loved contradicts the stigmatising beliefs that one becomes unacceptable and unlovable after HIV infection.

4.3.5.2 Raphael centre as primary source of support

The Raphael Centre, founded in 1999, is an NGO based in Grahamstown that provides care and support to those infected with or affected by HIV. Even though most of the women did not receive support from their families and were negatively affected by this, attending support group sessions helped by providing support in dealing with acceptance of their HIV-positive status, providing necessary information about living positively with HIV and also by providing space for the women to share their experiences and support one another. A support group is a gathering where people with similar problems, concerns and needs come together to support one another in a number of ways of daily living and functioning, emotionally, spiritually, physically and psychologically (Kalichman, Sikkema, & Somlai, 1996).

“Thanks to the Raphael Centre at least I have support and a place where I can come and talk without being judged or anything like that. I have also learnt a lot about living a positive life with HIV. Sometimes we get food parcels so those help us. But that is not the main reason I come to the support group, I come here because I know that I will not be insulted or treated badly because of my status. I see the people here like my family you know” (Busi).

Busi makes the interesting comment that while the food parcels are helpful, it is the acceptance that is offered to her at the centre that is the reason she returns. She implies that she is judged and treated badly elsewhere, but not at the centre, which highlights the importance of such organisations in the lives of those who are affected by HIV. Alongside this acceptance, participants value the information that they can access at the centre.

“What I have learnt is that as a person living with HIV you have to listen to what is being said about how to live with HIV. For example we get information about how to take the medication, so that means one has to do what they are told in order to live healthy and longer. Here at the Raphael centre they provide us with all the information we need about how to live positively and one must listen and do as told. I now also know the importance of using a condom. When you want a child you must make sure you go to the clinic first you know all those things. Life has changed now, I need to remember to take my pills at the right time and make sure I eat healthy you know” (Zintle).

All the participants noted how active participation within social support structures significantly reduced experiences of anxiety and uncertainty related to accepting their HIV-positive status. Social support is said to be beneficial in that it allows access to educational, emotional, and instrumental support processes. Perceived social support has received much attention recently (Kelly, Freeman, Nkomo, & Ntlabati, 2009). Studies have found that perceived social support is associated with adjustment to and coping with HIV diagnosis (Kelly et al., 2009). It also appears to be a factor that mitigates against mental disorder (Freeman et al., 2007).

“What changed was that I stopped being ashamed of talking about my status. I learnt that I should teach others in the location who knows little about HIV so that they can also be aware” (Nandi).

While their experiences of the support provided by the centre seem to be very positive, a negative is that in accessing this support, they run the risk of having their HIV status inadvertently disclosed to members of their community and experiencing stigma.

“Ummm, when I think about it, I think because we are being transported by the Raphael Centre's bus to and from our homes; so I think people who see us in the bus think ‘they have HIV and will get sick’. I think even if a guy liked me if they saw me in the bus they would stop liking me because they will know I am HIV-positive obviously because I go to the Raphael Centre. Some people say bad things but I don't really pay attention to those things. I know that people judge us when they see that bus” (Nandi).

“It's not easy, people think you're sick and will die and other people will say bad things about us when they see in the Raphael Centre's bus. Just things like ‘shame they are sick, they will die soon’. People pitying us I don't like that. Sometimes when you have argument with someone they will insult you because they have seen you coming from the support group with the bus, so they know that you are HIV-positive” (Busi).

It is very likely that the inadvertent disclosure that happens when people access the Raphael centre and its services, most specifically the transport that they provide to users, puts some people off ever seeking what is obviously a very important source of social support

Joining the support group, according to the findings of this study, is associated with both positive and negative experiences for the participants. The positives factors as discussed above were around having had an opportunity to acquire more knowledge about ways of living positively with HIV and that seem to have left them with a sense of empowerment. Having a safe space where there was sharing involved with no fear of being stigmatised or discriminated against seems to be valued by the centre clients. On the other hand, being part of a support group requires one to have accepted their status fully as it exposes people to the risk of inadvertent disclosure and resulting stigma.

4.3.5.3 Social support and ARV adherence

Several other authors found an association between social support and HIV-medication adherence. HIV related stigma and feeling unloved and uncared all seem to be barriers to treatment adherence. Most of the women struggled to adhere to their treatment the first time they started taking it and this could be a result of lack of support.

“Now what happened was because I was not getting enough support from home, I was not eating properly, so I defaulted treatment. I just stopped taking my medication. At this point I was not attending support groups, so I had no support at all” (Zethu).

Numerous studies have revealed that social support is related to improved outcomes and improved survival in several chronic illnesses, including HIV/AIDS (Gilbert, & Walker, 2009). Besides the positive influence of social support on the general well-being of HIV-positive individuals, social support seems to be an important factor in the behaviour of HIV-positive people, especially in terms of adhering to the demands of ARV prescriptions (Jones, 2005). The mechanism by which social support applies its beneficial effects is not fully understood, but practical assistance in achieving compliance, better access to health care, improved psychosocial and nutritional status and immune function, and decreased levels of stress may all play important roles (Jones, 2005).

4.3.6 Theme 6: Poverty

Many studies in South and Southern Africa have clearly confirmed that HIV/AIDS and poverty are locked in a circular relationship, with poverty creating the conditions that increase the risk of HIV infection and HIV infections contributing to a rise in poverty (Shisana et al., 2009). Poverty is a major cause of ill-health (Shisana et al., 2009), resulting in many thousands of preventable deaths that happen because people are unable to access adequate healthcare, with devastating shocks and stress on those remaining behind. Those affected households that struggle on are often headed by women or orphans and typically suffer further poverty because they are usually characterised by insufficient capacity to generate meaningful income (Shisana et al., 2009). The barriers created by poverty are extensive, as noted by Zethu below.

“For example it is difficult in this way, you are unemployed, you are HIV and you have no one supporting you. It’s even worse when you don’t know about the Raphael Centre. You try and apply for grant but it is being denied. You struggle because it becomes difficult to eat healthy when you don’t have the means to eat healthy. Food is a problem and shelter too sometimes” (Zethu).

Almost all the women who were interviewed were unemployed and reliant on a child support grant and a disability grant for financial support. Important to note, is that the resources that are needed to improve one’s situation are inaccessible to people in poverty, as noted by both Busi and Akhona.

“I can’t go back to school because there’s no money but at the same time I can’t really get a proper job with my standard five you see. I could not finish school because there was not enough money for me to do so. My mother drank the little money that she had you see, so ja” (Busi).

“Firstly I didn’t finish school and I want to go back to school but because of having no money I can’t. Also because Grahamstown is too small I can’t even start up a business because it will not flourish. I can do a lot of things like cooking or doing hair but because I don’t have money to start I can’t” (Akhona).

Shisana et al. (2009) report that poor living conditions that are a feature of living in poverty increase the risk of secondary infection with opportunistic diseases such as TB, a serious medical complication for people living with HIV. Three of the women reported having suffered from TB, which one can safely assume is most probably the result of their poor living conditions and lack of resources as most of them reported living in a shack without access to running water and electricity.

“So I was staying with her and I got sick with TB while I was with her. It was not nice, being sick is not nice yhoo!” (Zethu).

Poor living conditions also make ARV compliance more difficult because people are sometimes unable to have proper meals to take their medication or money to obtain transport to attend clinic appointments. This places HIV-positive people at risk of developing AIDS (Shisana et al., 2009).

“There are a lot of challenges, for example where I stay at night it’s like sleeping outside because it’s a shack so it’s very cold. I use paraffin stove at home so sometimes I don’t have money to buy the paraffin, so then I have to make fire with wood to boil water for bathing. Sometimes I run out of food so I’ll go to bed without having had something to eat. Sometimes I struggle for money to buy the candle to light at night, you know” (Nandi).

“I lived far, I lived in the coloured area, the lady who was my supporter lived in this coloured area, so it was too far and I could not manage to go get my treatment sometimes” (Zethu).

4.4 Conclusion

Six overlapping themes emerged from the data that deal with experiences of diagnosis, disclosure, stigma, ARV experiences, social support and poverty. The themes illustrate the range of structural barriers and other challenges that HIV-positive women in poverty face on a daily basis in trying to live their lives. The findings confirm that the prevention and treatment of HIV infections is not simply a matter of providing ARV medications, but require in addition to the individual treatment a range of systemic and structural changes.

CHAPTER 5: CONCLUSION

This study attempts to provide an account of the personal experiences of HIV-positive women living in poverty. It offers an indication of how these women deal with all the challenges of living with HIV while also living in poverty. The method used in this study is Interpretative Phenomenological Analysis, a qualitative method to access the participants' inner worlds that are revealed by analysing their personal descriptions of some of their experiences. The methodology provided the researcher with the necessary theoretical lens, data and tools of analysis to achieve the aims of the study, while at the same time affording a few marginalised women the opportunity to tell their stories.

While their individual experiences were of course varied, there were a number of important commonalities. Diagnosis, usually prompted by the occurrence of unexplained symptoms, is often traumatic and life-changing. Diagnosis of HIV infection is followed by the dilemma of disclosure, which most seem to manage by a partial disclosure to a few close family members or friends. While disclosure is necessary to obtain appropriate social support it also increases the risk that people will experience stigma and rejection. Their experiences of ARV treatment highlights the challenges of dealing with side-effects, which may result in inadvertent disclosure, and adherence. That a failure to adhere to ARV prescriptions is a seemingly common experience when first starting on the treatment is a worry, though fortunately the experiences reported here suggest that adherence becomes easier with time. Another important finding is that for these women, the support offered by the Raphael centre was crucial, even if the use of the transport that is provided by the centre can result in inadvertent disclosure. A solution might be to offer people unmarked transport or taxi fare instead, so as to not discourage people from seeking this support. Unfortunately, at the time of writing this thesis, a critical lack of funding had forced the centre to close its support group after nearly 14 years of successful operations. The experiences of the participants of this study suggest that this is a tragic turn of events. Lastly, all of the challenges that people face in living with HIV are compounded by their living in poverty, which deprives them of the resources they need to improve the quality and conditions of their lives.

5.1 Limitations of the Study

This research was restricted to a few isiXhosa-speaking African women, from a particularly deprived social group. These participants might be unusual in that they have been able to access and sustain a relationship with a prominent local NGO that offers support to those who are HIV-positive. The experiences of those unable or unwilling to access this NGO or others like it may be very different. Similarly, the findings are not (nor are they meant to be) representative of other groups of women from diverse cultural backgrounds and socioeconomic classes.

Another possible limitation in interviewing members of a support group is that their accounts might be influenced by what they might be expected to know and say as support group members.

Lastly, the interviews were conducted in isiXhosa and translated by the interviewer into English for analysis. The benefits of this are that the researcher would become very familiar with the material, which is a requirement of IPA, and that participants unable to speak English or Afrikaans are able to participate in the research. A limitation is that some of the meaning or richness of the data might have been lost in the translation. IPA involves a double hermeneutic whereby the researcher tries to make sense of the participants who try to make sense of the experiences, and translation adds a whole new layer of interpretation.

Nevertheless, despite the limitations described above, the findings are often consistent with other findings reported in the literature and supported by detailed excerpts that suggest that they are valid and meaningful.

5.2 Recommendations

Further research should consider the ways in which interventions could be designed to empower HIV-positive women who live in poverty. Such research would need to involve larger and more diverse population groups. The research findings presented in this thesis highlight the very important role that can be played by NGOs that support people who are HIV-positive. This should be made known to encourage sustainable funding from government and civil society.

It is also clear from this and other research that the care of people who are HIV-positive requires more than the prescription of life-saving pills. Emotional support and psychological care are also

crucial (Young, 2011). Structural changes that challenge the social, economic and political conditions to empower women and reduce stigma and poverty are also essential (Gupta, Parkhurst, Ogden, Aggleton, & Mahal, 2008). While their experiences and the challenges they face are almost unspeakable, it is also clear that the participants of this study are all very resilient and capable young women who only need a fairer social order in order to improve the conditions of their lives.

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APPENDICES

Appendix A



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INTERVIEW SCHEDULE FOR INDIVIDUAL INTERVIEWS

- 1) Can you tell me about your life?
- 2) Can you tell me how you found out about your HIV status?
- 3) What has changed about your life since finding out about your HIV status?
- 4) Could you please tell me about your experiences of living with HIV?
- 5) How would you describe yourself now that you are HIV-positive? [Probe: how has since changed]
- 6) Please tell me about how living with HIV affect your relations with others?
- 7) What do you think others think about you as a woman living with HIV?
- 8) Could you tell me about the challenges of being a women living with HIV?
- 9) Are you receiving treatment? If so, tell me about your experience of this?
- 10) Are you employed? If not what are the challenges of being unemployed?
- 11) Can you explain how you deal with those challenges?
- 12) What are your hopes about the future?

Appendix B



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AGREEMENT

BETWEEN STUDENT RESEARCHER AND RESEARCH PARTICIPANT

I (participant's name) _____ agree to participate in Thobeka Msengana's research project on my experiences of being on HIV-positive women in a local context

I understand that:

- 1) The researcher is an Intern conducting the research as a requirement for her degree at Rhodes University.
- 2) The researcher is interested in my experiences of living with HIV in Poverty.
- 3) I agree to participate in the individual interviews.
- 4) I am aware that participation in this study is voluntary and I can thus choose to withdraw at any time.
- 5) I will be asked to discuss matters that will be of a serious and sometimes personal nature. I recognise that I have the freedom to opt out of discussing anything that makes me uncomfortable.
- 6) If I experience any distress whatsoever, I am aware that the Rhodes psychology clinic is available should I feel the need to discuss anything.
- 7) My identity will not be disclosed in the research findings and I am aware that my anonymity and right to confidentiality will not be violated.
- 8) I am aware that the interview will be audio recorded and that the recordings will be transcribed for interpretation, after which the recording will be erased.

Participant signature: _____

Researcher signature: _____

Date: _____

Appendix C



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Counselling Centre • Tel: (046) 603 7070 • Fax: (046) 636 7071 • e-mail: d.gelderbloem@ru.ac.za

Ms Jabu Van Niekerk
Director of the Raphael Centre
Grahamstown
01 March 2013

Dear Ms Van Niekerk

Permission to approach Raphael Centre Clients to recruit research participants

I am currently an Intern at the counselling centre at Rhodes University. I am conducting a research project on HIV and women as part of the requirements of this course and have attached a copy of my research proposal for your consideration. The proposal has received the approval of the Rhodes University Psychology Department's Research Proposal and Ethics Review Committee. The research is supervised by Dr Charles Young of the Psychology Department.

The aim of the research is to explore the lived experiences of HIV-positive women in poverty. As the Raphael Centre is the major HIV organisation in Grahamstown that works directly with HIV-positive people, I would like to request for your assistance in locating participants for my research project. I would be glad to meet with you to discuss my research plans in more detail.

Yours sincerely

Ms Thobeka Msengana

Intern Counselling Psychology

Email: t.msengana@ru.ac.za, Cell: 0735986236