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**AN IN-DEPTH ANALYSIS OF THE PSYCHOLOGICAL CHALLENGES
ASSOCIATED WITH DISCLOSING AN HIV/AIDS-INFECTED STATUS
AND THE IMPACT ON ARV-TREATMENT ADHERENCE AMONGST
WOMEN ON ARV- TREATMENT LIVING IN A CAPE TOWN TOWNSHIP**

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A dissertation submitted in fulfilment of the requirements for the award of the degree
of Masters in Psychological Research

Faculty of the Humanities

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2006-12-12

COMPULSORY DECLARATION

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has also been cited and referenced.

Signature:

Date:

ACKNOWLEDGEMENTS

A lot of people have contributed in a variety of ways towards the construction of this work. They referred me to studies and books, engaged in discussions and suggested possible ways to approach my work. I thank them all for their contribution.

I owe a great debt of gratitude to the various funding organisations that have contributed towards the completion of this work i.e. NRF; Harry Crossley Scholarship; UCT Council B Scholarship; The Siri Johnson and the KW Johnstone Research Scholarship. I am also indebted to the staff members of the Postgraduate Funding Office, in particular to Zanele Magwa and Nomnikelo Gqwabe, for their ever-willingness to assist.

I am indebted to my dear mother for the support, encouragement and the great sacrifices she makes daily in order for me to be able to further my studies.

I owe a great deal of gratitude to my supervisor and mentor “Sis Pumla”, Prof Pumla Gobodo-Madikizela, who has played a major role in a variety of areas of my life, besides guiding me towards the completion of this work. Her return to UCT has signified countless blessings for a number of students besides myself. I would like to thank her for her patience and tolerance with my working pace; for her humanness displayed by picking up the phone to merely ask how the work was going while it was still under construction and for her constant encouragement. Working with her has been a true privilege.

I also wish to express my tremendous gratitude to the founder and co-ordinator of Luvuyolwethu, Selina Poswayo, for introducing me to the women of Luvuyolwethu. I wish to acknowledge the important and unpaid work that she, together with her assistants, do in providing support for the women without receiving any formal financial support. I truly admire their selflessness.

I would like to thank the women of Luvuyolwethu for their willingness to open their hearts and share their rich lived experiences with me. My interactions with them have had a great influence on myself as a person and as a researcher.

I owe a great debt of gratitude to my editor, Diana Henning, for her availability; punctual feedback and for the role she played in helping me improve my text. Thanks Di.

Many thanks go to the endless list of people who contributed during the early stages of the inception of this work. I mention a few; people such as Beth Mills; Francis Morris; Celia Walters; Dr. Elaine Salo; Dr. Jane Bennett; Lee Padayachee and Moeketsi Mosomothane. My deepest gratitude goes even to those that I have not mentioned and who played a role towards this study.

Lastly to the special friends who have walked this journey with me through their constant encouragement: Coceka Mfundisi; Mashudu Nefhere; Bandisiwe Cabangana;

Unathi Ngxamngxa; Thozama Qwebani; Zuki De-Wet; Botle Lerotholi; Nontando Nkangana and Maserame Matshediso. You have been inspiring friends indeed.

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ABSTRACT

The availability and free-access of ARV-treatment in South Africa has been a signifier of hope amongst fellow South Africans. This in effect has led to the government's assumption that the disclosure of an HIV/AIDS-infected status would be easier due to the treatment's effectiveness. Disclosing an HIV/AIDS-infected status to the individual/s with whom one cohabits with, has thus been made a policy by the government in order to be able to access ARV-treatment. This study examined the psychological challenges associated with disclosing an HIV/AIDS-infected status to the individuals one lives with, and the possible impact that such challenges have on ARV-treatment adherence. A purposive sample of 10 HIV-positive women on ARV-treatment who varied in age, was drawn from a township HIV/AIDS-voluntary organization. Results show that fear-related justifications emerged as common reason for participants to abstain from disclosing an HIV/AIDS-infected status to the individuals they cohabited with, and thus relied on pretending to suffer from various other illnesses instead of HIV/AIDS. Results furthermore, highlighted an emergence of two forms of treatment taking and adherence to ARV-regimen, which resulted from participant's pretence from the various illnesses. Some of the participants went through the daily practice of taking their ARV-medication in secret from individuals they lived with, so as to conceal their HIV status. Other participants on the other hand, went ahead and took their treatment in the presence of those they cohabited with. Thus, results highlighted a correlation between taking treatment in secret and treatment non-adherence, as well as a correlation between taking treatment in the presence of individuals with whom participants lived with and treatment adherence. Recommendations to adjust the policy are suggested.

TABLE OF CONTENTS	PAGE
ABSTRACT	i
ACKNOWLEDGEMENTS	ii
TABLE OF CONTENTS	iii
<u>CHAPTER 1</u>	
BACKGROUND	1
<u>CHAPTER 2</u>	
LITERATURE REVIEW	
2.1.1) Women and HIV/AIDS stigma	2
2.1.2) The purpose of stigmatization	8
2.1.3) ARV-treatment and disclosure	10
<u>CHAPTER 3</u>	
RESEARCH METHODOLOGY	
3.1.1) Qualitative Research	14
3.1.2) Aims of the Study	14
3.1.3) Research Design	15
3.1.4) Sampling	15
3.1.5) Data Collection	16
3.1.6) Data Analysis	16
3.1.7) Ethical Consideration	17
<u>CHAPTER 4</u>	
PARTICIPANTS' BACKGROUND AND RESEARCH FINDINGS	
4.1) PARTICIPANTS' BACKGROUND	18
4.2) RESEARCH FINDINGS	22
4.2.1) "FEAR OF NEGATIVE OUTCOMES"	23
a) Fear of exacerbating the illness of already ailing elderly parents	23

b) Fear of being accused of promiscuity	24
c) Fear of being rejected by the partner and	28
d) Fear of losing economic support	32
4.2.2) “DISGUIISING AN HIV-POSITIVE STATUS”	34
4.2.3) “ARV- TREATMENT TAKING STRATEGIES”	36
4.2.4) “ARV-TREATMENT ADHERENCE AFTER DISCLOSURE”	44
4.2.5) SIGNIFICANCE OF SUPPORT GROUPS	50

CHAPTER 5

DISCUSSION

5.1) Discussion of Research Findings	52
5.1.1) Fear of exacerbating the illness of already ailing elderly parent	52
5.1.2) Fear of being accused of promiscuity	53
5.1.3) Fear of being rejected by the partner	55
5.1.4) Fear of losing economic support	57
5.1.5) Disguising an HIV-positive status	59
5.1.6) ARV-treatment taking strategies	60
5.1.7) Disclosure and patterns followed when taking treatment	64

CHAPTER 6

STRENGTHS AND LIMITATIONS OF RESEARCH	68
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CHAPTER 7

IMPLICATIONS AND RECOMMENDATIONS	70
7.1.1) Counselling Services	70
7.1.2) Attempts to de-stigmatise HIV/AIDS	71
7.1.3) Support Groups	72
7.1.4) ARV-Access Policy	73

CHAPTER 8

RECOMMENDATIONS FOR FURTHER STUDY	77
-----------------------------------	----

CHAPTER 9

REFLEXIVITY	78
9.1.1) Establishing rapport with the participant	78
9.1.2) Power differences	79

CHAPTER 10

CONCLUSION	83
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REFERENCE LIST	85
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APPENDICES

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CHAPTER 1

BACKGROUND

The response to the HIV/AIDS epidemic has sparked a series of controversies in South Africa. Among the controversies are the following: the country's president questioning the link between HIV and AIDS; the existence of so-called miracle AIDS cures; the toxicity of anti-retroviral treatment, and the events at the recent Toronto conference where South Africa's Minister of Health emphasized the benefits of nutrition over anti-retroviral medication (Kahn, 2006). The Minister's views on HIV and AIDS were not only made visible through the displays of garlic, lemon, beetroot and potatoes, which the Minister presented at South Africa's stand at the exhibition, but during her presentation, she went so far as to argue that what was on display represented South Africa's best practices towards treating the virus. Unlike the displays of the various vegetables, ARV's were initially not on display (Kahn, 2006). This view, has been held and promoted by the Minister of Health since 2003 (Abdool Karim & Abdool Karim, 2005), despite scientific evidence showing a lack of evidence that the concoction of vegetables (as prescribed by the Minister) is in fact able to boost the immune system (Thom, 2006).

Furthermore, several studies have demonstrated the benefits of anti-retroviral treatment in boosting the immune system, thus leading to an improvement in health, delaying the onset of AIDS and the decline in HIV/AIDS-related mortality (Abdool Karim & Abdool Karim, 2005; Mugavero & Hicks, 2004). The Minister's views have been and still continue to be detrimental to individuals who, after hearing such messages, switched from ARV's to the prescribed vegetables. Such views are detrimental to those who do not want to take ARV's, and who rely on nutrition instead, despite having a CD 4 count of less than 200, which signals an AIDS-infection stage at which the compromised immune system can improve only through the use of ARV-medication.

The government's national anti-retroviral access policy requires HIV/AIDS-infected individuals to disclose their status to someone who cohabits with them. The rationale for this policy stems from the government's assumption that anti-retroviral treatment improves the state of health by delaying the onset of the virus, and thus prolonging life. The government hopes that the stigma surrounding HIV/AIDS will therefore end

because infected individuals are seen as 'normal' or similar to non-infected individuals. Given such reasons, the government thus assumes that it would be easier for individuals to disclose their HIV/AIDS-infected status in order to 'normalize' the virus. However, this may not necessarily be the case in reality. Even government cabinet members and other prominent public figures, who have been invited to talk about their HIV-infected status, are reluctant to do so. These talks are part of an initiative aimed towards raising awareness and 'normalizing' the virus in order to work towards ending the stigma surrounding HIV/AIDS. Very few leaders in government, thus far only Chief Mangosuthu Buthelezi, Dr. Nelson Mandela and Ruth Bhengu, have made public disclosures about their children passing away from the virus. In contrast, the then ANC Youth League leader Peter Mokaba argued that ARV medication in fact causes AIDS (Haffajee, 2002). Mokaba's HIV-status, as well as that of Parks Mankahlana, spokesman for both then president Dr. Nelson Mandela and current president Thabo Mbeki, only became public after their death. This clearly sends the message that disclosing one's HIV/AIDS-infected status is not 'acceptable' or 'okay.' The continuing silence by leaders in turn encourages the stigma around HIV/AIDS, thus contributing to lay people's fear of disclosing their HIV status, which is not surprising if the same people who encourage disclosure do not disclose themselves.

In addition, studies have shown that it is particularly challenging for women to disclose their HIV-status (Allen, 2003; Campbell, 2003; Odhiambo & Maina, 1998; Raisler & Cohn, 2005). instead of them identifying and disclosing to their immediate family members, they would rather deceive health officials and present trusted acquaintances as family members (Allen, 2003)..

Additionally, in cases where women were receiving treatment but had not disclosed their infected status to the members of their households, they would either skip medication, (especially if people happened to be around when they had to take their medication) or they would modify their dosing times (Daya et al., 2004; Odhiambo & Maina, 1998; Ware, Wyatt & Tygenberg, 2006). Such results indicate that, although the government's national anti-retroviral plan has offered HIV/AIDS-infected individuals an opportunity to access treatment to improve their health, the disclosure of an HIV/AIDS-infected status remains a contentious issue. It is therefore the aim of

this study to investigate why it is so hard for HIV/AIDS-infected individuals to talk openly and directly about their HIV status, even if they are undergoing effective treatment.

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CHAPTER 2

LITERATURE REVIEW

An introduction to this study is offered by reviewing literature on the psychological challenges associated with disclosing an HIV/AIDS-infected status and the impact such challenges have on adhering to ARV-regimen. It ends off by highlighting the motivation and the aim of its implementation.

Women and HIV/AIDS stigma:

South Africa is home to approximately 2% of the world's population, yet an estimated 30% of the population is living with HIV/AIDS (Stewart, Padarath & Bamford, 2004). Such high statistics of HIV/AIDS in South Africa has led to it to be regarded as the country with the worst epidemic in the world (Nattrass, 2002; Dorrington, Bourne, Bradshaw, Laubscher & Timeous, 2001) with women being the hardest hit by the epidemic (Dorrington, Bradshaw & Budlender, 2002; Strebel, 1992). Statistics show that not only are women more vulnerable than men to HIV transmission, but they are also the most infected.

Previous research has shown that despite the high prevalence of HIV/AIDS in South Africa, the virus continues to be stigmatised (Crewe, 2002; Rohleder, 2004) as individuals infected with it tend to be negatively viewed by society (Jewkes, 2006; Lee & Craft, 2002). HIV/AIDS-related stigma is defined by Stein (2003) as a deviance accorded to an individual due to his or her HIV/AIDS-infected status. The individual is seen as one who has contravened social laws and is thus viewed as 'abnormal' - in other words s/he acquires a 'spoiled identity' due to certain characteristics, in this case HIV/AIDS, and thus is subject to discrimination (Deacon, 2005; Herek & Capitanio, 1998). The notion of 'stigma,' which was inspired by Goffman (1968), was used to refer to bodily characteristics designed to highlight disgrace concerning an individual's moral status. According to Goffman (1968), in Ancient Greece individuals who failed to conform to social norms and values had signs cut and burnt into their bodies to symbolise their social contraventions. These marks were termed 'stigma' and individuals possessing them were regarded as

'abnormal' and were thought to be avoided (Deacon, 2005; Taylor, 1991; Goffman, 1968).

Similar to how the notion of stigma was applied in the past, various researchers have identified characteristics that have led to HIV/AIDS being recognised as a stigmatized condition: Firstly, they suggest that HIV/AIDS is a disease whose cause arises entirely through the actions of the individual, because it is considered to be transmitted through voluntary behaviours (Herek, 2002; Holzemeyer & Uys, 2004; Sontag, 1988). Such voluntary behaviours have been largely reinforced by the South African HIV/AIDS ABC Campaign aimed at combating the spread of HIV/AIDS (Campbell, 2003). According to the campaign, the A promoted sexual abstinence, the B promoted faithfulness i.e. having one sexual partner and the C encouraged condom-use (Campbell, 2003). In other words, the implication around the HIV/AIDS ABC Campaign was that, the acquisition of HIV/AIDS was a 'confirmation' of an identity (Sontag, 1988) which had contravened the moral laws that should have been practised in order to avoid contracting the virus.

Campbell (2003) however argues against the perspective of the HIV/AIDS ABC Campaign and maintains that not only is the campaign dominated by behavioural understandings of sexuality, but it ignores the complicated forces involved in shaping sexual behaviours. As an example of the intricacies involved in shaping sexual behaviour, individual studies conducted by Abdool Karim, Soldan & Zondi (1995); Campbell (2003) revealed that although sex workers knew how HIV/AIDS could be transmitted, not using a condom with clients was significant amongst sex workers, as it protected them from violent clients who claimed that the use of a condom left them sexually unsatisfied. Also, the lack of condom use was a form of securing more income compared to when a condom is used (Abdool Karim et al., 1995; Campbell, 2003).

The second suggested reason for the stigmatization of HIV/AIDS is due to its progressive and deadly nature if it goes undetected (Herek, 2000; Holzemeyer & Uys, 2004). Cadwell (1991) asserts that up until the manifestation of the AIDS endemic, there had been a tendency for the topic of death to be postponed or restricted to certain ailments, however, the HIV/AIDS endemic has been viewed as contributing to

the destruction of such a social order. Consequently, a vast number of young HIV/AIDS-infected individuals have been compelled to confront the reality of mortality, irrespective of age.

Thirdly, the initial association of HIV/AIDS with homosexuality has contributed to the stigma attached to the virus (Conrad, 1986; Crandall & Coleman, 1992; Deacon, 2005; Sontag, 1988). For instance, the association of homosexuality with forbidden 'sodomy' and the unprotected sexual nature of the transmission of the virus, has led to it being regarded as a disease of 'abnormal' sexual practices (Conrad, 1986) and sexual indulgence (Sontag, 1988).

Fourthly, the fact that HIV/AIDS is both incurable and that its characteristics such as emaciation, skin lesions and dementia (Deacon, 2005) become visible in the progressive stages of the disease, is another reason why HIV/AIDS is stigmatised. Sontag (1988) maintains that the characteristics associated with HIV/AIDS are associated with stigma because they are 'dehumanizing,' as they 'reveal' an 'identity,' which may have been kept a secret, had the HIV/AIDS-related characteristics not been visible.

Additionally, seeing that HIV/AIDS is more prevalent among poor individuals and females, it has come to be synonymous with poverty and women (Deacon, 2005). Poor people were stigmatized, seeing that they were unemployed - thus they have been viewed as having a heightened sexuality (Levine & Ross, 2002). Women on the other hand, dating back to biblical times, are associated with the persona of Eve and have thus been viewed as the source of evil (Bunting, 1996; Keller, 2004) and their biological processes have been viewed as posing a danger to males (Duffy, 2005; Leclerc-Madlala, 2002). For instance, in her ethnographic study, which she conducted in St. Wendolin, Kwa-Zulu Natal, Leclerc-Madlala discovered that women's biological processes such as menstrual blood (Leclerc-Madlala, 2002), "vaginal discharges and lubrications" (Leclerc-Madlala, 2001:542) are considered to be naturally contaminating as they are seen as the carriers of the 'danger' i.e. HIV/AIDS virus. Leclerc-Madlala (2002) maintains that similar associations were not made between males and HIV/AIDS in St. Wendolin, thus males were absolved of responsibility for HIV/AIDS transmission. Women's blame for the transmission of

HIV has been further endorsed by cultural practices such as female virginity testing (Leclerc-Madlala, 2001), a practice aimed at combating the spread of HIV/AIDS.

Goffman (1963) maintains that the process of stigmatization goes beyond identifying certain characteristics as 'deviant' but extends through the use of language as well. For instance, in the study conducted by Dowling (2002) in various areas of Cape Town whereby she examined how HIV/AIDS was named and talked about by African language speakers, she discovered that stigmatisation of HIV/AIDS through the use of language took its form through the use of negative stigmatising language. For instance, metaphors such as "*umabulalabhuqe*" (the indiscriminate killer); "*udubul'egeqa*" (the one who shoots to kill); and "*ugawulayo*" (the one who chops down) are amongst the metaphors that are referred to when talking about HIV/AIDS (Dowling, 2002). Such metaphors translate or associate HIV/AIDS with death and encourage infected individuals to be stigmatized or treated 'uniquely' as they are seen as individuals who ought to be feared because they have a deadly condition.

HIV/AIDS euphemisms, on the other hand took their form through a special language called "*ukuhlonipha*" (Pinnock, 1988 as cited in Dowling, 2002) which entails not mentioning the acronyms "HIV/AIDS," but instead to use a 'less intense language' when talking about it. For instance, she offers examples of some of the euphemisms that are used to refer to an HIV/AIDS-infected status such as "*amagama amathathu*" (three letters) for HIV and "*amagama amane*" (four letters) for AIDS-both referring to the HIV/AIDS acronyms.

Similar to the use of acronyms when talking about HIV/AIDS, the study conducted by Mills in KTC demonstrated that talking about HIV/AIDS also took the form of hand-signalling, i.e. through showing three fingers or making the sign of a cross with the two index fingers (Mills, 2006). The participants in Mills's study explained that the showing of three fingers stood for each letter of the acronym 'HIV' whereas the sign of the cross made by the two index fingers symbolised the crosses that are put on the graveyard just after the person has been buried - this symbolises the threat that HIV/AIDS poses to one's life (Mills, 2006). The use of such metaphors and euphemisms when referring to HIV/AIDS are used to render HIV/AIDS-infected individuals as 'other' or different from 'normal' uninfected individuals (Mills, 2006).

The purpose of stigmatization:

According to Hendler (2003); Tewksbury and Mac Gaughey (1997), when society is faced with a situation that overwhelms the social order, it may attempt to escape; it may control it either by inactivating or destroying its causal factors; it may deny it; or it may displace the fear that the situation brings about in an attempt to alleviate the anxiety that it causes. For instance, the incurability of HIV/AIDS is a challenge to the moral order because it undermines society's attempt i.e. through medical science, to keep the illness under control. Thus, in an attempt to control the anxiety caused by the HIV/AIDS epidemic, individuals engage in a process of 'othering' i.e. they blame individuals in different social categories in order to distance themselves from the epidemic. They do this by attributing HIV/AIDS susceptibility to 'other' i.e. blame members of the 'outgroup' for possessing characteristics different from theirs, and which put them at risk for contracting HIV/AIDS (Hendler, 2003). For instance, individuals such as sex workers, black people, homosexuals and intravenous drug users (Tewksbury & Mac Gaughey, 1997), have been amongst the individuals who have been blamed for possessing characteristics, which put them at risk for contracting HIV/AIDS (Deacon, 2005; Tewksbury & Mac Gaughey, 1997). Such HIV/AIDS 'susceptibility' characteristics have also been endorsed by the HIV/AIDS ABC campaign, which regards individuals who transgress the "ABC" laws of HIV/AIDS prevention to be at risk of contracting the virus (Campbell, 2003).

However, Joffe (1999) maintains that the status of 'outgroup' members is not fixed, but instead depends on power relations within a specific context. For instance, Joffe's work has shown that whereas some black South Africans blame Western scientists for the spread of HIV/AIDS, a number of British heterosexual males blame Africans for it. Nonetheless, irrespective of who acquires the label of 'outgroup' members and who is blamed, the core function of scapegoating/stigmatisation is to differentiate and establish boundaries between those perceived to be at risk and those who are not (Hendler, 2003; Skinner, 2004). This categorisation is functional to 'ingroup' members because it reduces the anxiety that infection could happen to 'ingroup' members as well (Coleman, 1986; Hendler, 2003).

According to Bunting (1996); Campbell, Yugi and Maimane (2006) the process of HIV/AIDS stigmatization cannot be detached from gender inequalities resulting from ideas about masculinity and femininity. For instance, the association of masculinity with dominance and femininity with subservience has resulted in the fact that men's promiscuity is more easily tolerated than in the case of women who become infected (Duffy, 2005; Raisler & Cohn, 2005). Such gender imbalances have contributed to the decision by women to remain silent about an HIV/AIDS-infected status. For example, studies have shown that women are reluctant to disclose their HIV/AIDS-infected status as disclosure was associated with feelings of guilt, emanating from the idea that one has failed to play a certain role in a relationship either as wife, partner or parent (Ndaba, 2002), fear of being blamed and being labelled promiscuous (Campbell, 2003), as well as the dread of being rejected even in cases where they have remained monogamous to their partners (Bharat & Aggleton, 1999; Derlega, Winstead, Greene, Serovich, Elwood, 2004; Skinner & Mfecane, 2004;). The blame accorded to women for being HIV/AIDS-infected puts women at risk of violence and the possibility of abandonment (Raisler & Cohn, 2005), resulting in impoverishment, because compared to males, females are economically disadvantaged (Shabodien, 2003; Soskolne, 2002). The act of maintaining silence in such instances is considered to be significant as it protects women from the possibility of discrimination (Ciambrone, 2003; Kimberly & Serovich, 1995).

On the other hand, various theorists have argued that it is important for an HIV/AIDS positive status to be disclosed. In this way individuals can cope with the negative stressors associated with HIV/AIDS-infection such as self-blame, lack of self-worth (Codwell, 1991); the physical manifestations of the condition, concerns about death and strict compliance to treatment (Derlega et al., 2004); feelings of shame, embarrassment, loneliness and depression (Brown, 1999; Hendler, 2003). In addition, Williamson (1995) as cited in Hendler (2003) asserts that it is important for HIV/AIDS-infected individuals to disclose, particularly to their families, as despite the professional intervention or support offered by HIV/AIDS experts, the infected individual comes to depend on the family system while she is ill. Thus, Preston-Whyte (2001) similar to Williamson encourages disclosure to family and maintains that it is through family support that the infected individual can cope with the adverse challenges of chronic illnesses such as HIV/AIDS.

However, studies by Corner, Henker, Kemeny & Wyatt (2000); Deacon (2005); Kahn (2004) argued that disclosing an HIV/AIDS-infected status does not necessarily lead to cathartic benefits - instead studies by these theorists revealed that the disclosure of an HIV/AIDS-infected status was correlated with increased psychological distress rather than its reduction. There are various possible reasons, which have been proposed, that contribute to the increase in psychological distress. This is when women disclose an infected status, particularly within their families, and run the likelihood of being excluded from household activities (Labov, 2006; Strebel, 1993). There is also evidence that, compared to males within the same household, young widows who live with their husband's extended family are likely to receive less support once their status is known (Rivers & Aggleton, 2000). Instead, they could run the risk of losing legal protection in their quest to inherit their husband's belongings (Rivers & Aggleton, 2000). Thus the possibility that they may experience adverse consequences once they make their infected status known encourages women to maintain silence about their status so as to protect themselves. (Stein, 2005).

ARV-treatment and disclosure:

The availability of ARV-treatment has been viewed as a process that would facilitate the road to disclosure (Mkosi, 2000; Stewart et al., 2004): thus the South African government's announcement made in November 2003, about a national plan to provide free anti-retroviral medication to those who are or have been infected with the HIV-virus and who have made their status known to their family member (Stewart et al., 2004), marked a significant milestone in the country's response to the HIV/AIDS epidemic (Abdool Karim & Abdool Karim, 2005). Until then, the HIV/AIDS epidemic had been dominated by a variety of controversies, ranging from bogus AIDS cures (Abdool Karim & Abdool Karim, 2005), debates on the benefits of nutrition vs ARV treatment and debates on HIV prevention strategies rather than the provision of ARV treatment (Abdool Karim & Abdool Karim, 2005; Stein, 2005). HIV/AIDS was thus viewed as an inevitable death sentence that would eternally shadow South Africa, since conventional wisdom maintained that access to treatment would be impossible for individuals residing in low-and middle-income areas (Stewart et al., 2004; UNAIDS, 2000).

The association of ARV treatment with lowering the amount of HIV in the blood, thereby preventing the virus from multiplying leading to less compromise of the immune system and life prolongation (Abdool Karim & Abdool Karim, 2005; Siegel & Scrimshaw, 2005) has led to theorists to deduce that not only has the advent of anti-retroviral treatment led to the de-stigmatisation of HIV/AIDS due to its effectivity in reducing HIV, but it has brought changes to both the meaning and the experience of living with HIV/AIDS (Adam, 2003; Klitzman, Kirshenbaum, Dodge, Remien, Ehrhardt, Johnson, Kittel, Daya, Morin, Kelly, Lightfoot, Rotheram-Borus, 2004). This is because the drugs have shifted or changed stigmatising perceptions of the virus from being viewed as incurable and deadly to being regarded as chronic, but manageable (Johann-Liang & Lee, 1990; Muula & Mfutso-Bengo, 2005; Venter and Sanne, 2003). Such a shift has been said to encourage HIV/AIDS-infected individuals to disclose in order to have access to treatment, because it instils hope amongst them (Siegel; Lekas and Schrimshaw, 2005; Stein, 2005).

Deacon (2005) has however maintained that although anti-retroviral treatment may be available, such availability does not necessarily encourage women to disclose their HIV/AIDS-infected status. Instead, due to the stigma attached to HIV/AIDS, a variety of issues come into play when women decide whether or not to disclose and to access anti-retroviral treatment. For instance, compared to men, women have been said to be more reluctant to disclose an HIV/AIDS-infected status (Allen, 2003; Campbell, 2003; Odhiambo & Maina, 1998; Raisler & Cohn, 2005) and to access anti-retroviral treatment (Campbell, 2003; Mac Donald et al., 2001). Part of this anxiety may emanate from the various adverse effects associated with women when they disclose an HIV/AIDS-infected status, which entails ostracization by both family and community (Campbell, 2003; Rohleder, 2004); physical abuse (Raisler & Cohn, 2005) and the threat of being killed (Jewkes, 2006). Not surprisingly, these factors have all played a role in encouraging women to maintain their silence.

This silence however, has implications for both accessing (Duffy, 2005; Stewart et al., 2004) and adhering to treatment (Ware et al., 2006). For instance, studies by Campbell (2003); Duffy (2005); Stewart et al., (2004) have shown that due to the fear of stigmatization, should their status become known, women opted not to access HIV/AIDS-related information and treatment. Such studies illustrate that irrespective

of the presence of ARV treatment, the stigma attached to HIV/AIDS interferes with the preliminary steps of ARV regimen i.e. obtaining information about treatment and accessing it.

In addition, the fear of one's status being discovered has led to women hiding and modifying their dosing schedules (Daya et al., 2004) as a means of maintaining silence about their infected status. Such behavioural manifestations are however problematic as through hiding and modifying dosing schedules, individuals would either not take the treatment at all or not adhere to the specific scheduled times for taking the medication – all these are factors which impact on the effectiveness of ARV treatment (Abdool Karim & Abdool Karim, 2005).

Women's fear of disclosing an HIV/AIDS-infected status is great - to the extent that it puts their children's lives at risk too (Raisler & Cohn, 2005; Rankin, Brennan, Schell, Laviwa, Rankin, 2005). For instance, in cases whereby Nevirapine (which reduces the risk of mother-to-child transmission) is prescribed, women are advised to avoid breastfeeding while taking it. However, because women are afraid to disclose their status, they proceed and breastfeed their infants (International Family planning Perspective, 2001). This is particularly prevalent in environments or cultures which favour breastfeeding (Raisler & Cohn, 2005). The failure to breastfeed and opt for formula feeding instead has come to be considered as an indirect revelation of one's HIV/AIDS-infected status (International Family Planning Perspective, 2001). This example illustrates that the dread of being stigmatized is so extreme that women would rather run the risk of putting their children at risk of also being infected rather than disclose their HIV/AIDS-infected status.

The government's national anti-retroviral access policy requires HIV/AIDS-infected individuals to disclose their status to someone who cohabits with them. The rationale for this policy stems from the government's assumption that anti-retroviral treatment improves the state of health by prolonging the onset of the virus, thereby increasing the prolongation of life. The government hopes that the stigma surrounding HIV/AIDS will therefore end because infected individuals are seen as 'normal' or similar to non-infected individuals. Given such reasons, the government thus assumes that it would be easier for individuals to disclose their HIV/AIDS-infected status. As

evidenced in various previously conducted studies, the government's suppositions may not necessarily hold. For instance, studies have shown that disclosing an HIV/AIDS-infected status is such a challenge that instead of women identifying their immediate family members, they would rather deceive health officials and present acquaintances as family members. Additionally, in cases whereby women were on treatment and had not disclosed their infected status, they would either skip medication, especially if people happened to be around when they had to take their medication, or they would modify their dosing times (Daya et al., 2004; Odhiambo & Maina, 1998; Ware et al., 2006). Such results indicate that although the government's national anti-retroviral plan has offered HIV/AIDS-infected individuals the privilege of accessing treatment to improve their health, disclosure however still remains an issue. It is therefore the aim of this study to investigate what it is about disclosure that makes it hard for HIV/AIDS-infected individuals to talk openly and directly about an HIV/AIDS-infected status even if they are undergoing effective treatment.

University of Cape Town

CHAPTER 3

RESEARCH METHODOLOGY

This chapter focuses on the research methods that were used in this study. It does this by outlining and providing justification for each method that was implemented to collect data. It ends off by highlighting the ethical factors that were taken into consideration.

3.1.1) Qualitative Research:

A qualitative research design was used in this study. The vital point of qualitative research is that it allows the researcher to learn and explore the social or human problems as they are experienced or lived by the participants (Crosswell, 1998).

3.1.2) Aims of the Study:

According to the government's antiretroviral access policy, HIV/AIDS-infected individuals are required to disclose their status to someone with whom they cohabit with in order to have access to treatment. The rationale for the policy emanates from the government's assumption that, because anti-retroviral treatment is effective in improving the state of health of HIV/AIDS-infected, the stigma surrounding HIV/AIDS will therefore end because infected individuals are seen as 'normal.' The government assumes that it would thus be easier for infected individuals to disclose their status.

Studies have however shown that the government's hypothesis may not necessarily hold. For instance, although anti-retroviral treatment has been made available and has proven to be effective, the issue of disclosing an HIV/AIDS-infected status still remains a challenge. It is therefore the purpose of this study is to investigate the psychological challenges associated with disclosing an HIV/AIDS-infected status and how such challenges impact on ARV-treatment adherence.

3.1.3) Research Design:

In-depth, semi-structured interviews were conducted in *IsiXhosa* and translated into English as a means of data collection. In-depth semi-structured interviews are defined by Kvale (1983; 1996) as informal interviews that are guided by a sequence of predetermined questions and themes to be covered during the interview session. In-depth interviews were chosen as the most appropriate technique of data collection in this study as they allowed the interviewees the power of giving detailed knowledge on the topic in a manner they wished to. Presenting participants with such power enhanced the possibility of the interviewees going into novel areas, which might not have been anticipated by the interviewer (Radnar, 1994; Smith, 2003).

In addition, focusing on in-depth interviews in a semi-structured format offered the interviewer the privilege of collecting rich data as it exposed the researcher to go beyond focusing on the questions to be pursued during the interview session, but to also be exposed to the various gestures made by the interviewee while being interviewed. Additionally, it allowed the interviewer to be an active listener through probing and following up on the responses the interviewee offered during the interview session.

3.1.4) Sampling:

A Purposive sampling was used as a technique of sampling in this study. Silverman (2001) defines purposive sampling as a sampling method that allows the researcher to work with participants who best meet the purpose of the study. The sample for this study consisted of ten HIV positive women on anti-retroviral treatment, ranging between the ages of 23 and 50, who are working with the *Luvuyolwethu* Organisation. *Luvuyolwethu* Organization is a voluntary organization based in KTC (an informal settlement in Cape Town), which consists of a group of women undergoing anti-retroviral. Selina Poswayo who is the founder and co-ordinator of the organisation was responsible for selecting the group of women I interviewed. Women were specifically chosen for the purpose of this study, because compared to males, not only are they the hardest hit by the epidemic, but they are said to be biologically and socially more vulnerable to the transmission of HIV. In addition, Cape Town has

been chosen as the site of focus as it has been the first city to provide anti-retroviral treatment in South Africa.

The reason for limiting the sample of this study to ten participants is because it aims to explore some of the psychological challenges associated with disclosing an HIV/AIDS-infected status and the impact on adhering to ARV-treatment, thus the results of this study may not necessarily be generalizable, but are specifically relevant to this particular group of women. Additionally, the reason for focusing on this group of women is because although they may differ in age, they come from similar cultural or communal background that could shape the various challenges associated with disclosing an HIV/AIDS-infected status they are faced with and the impact of disclosure or lack thereof has in terms of adhering to ARV-treatment.

3.1.5) Data Collection:

The interview took place at the University of Cape Town's Child Guidance Clinic and participants were interviewed individually. Material was gathered through audio-taped, in-depth, semi-structured interviews, which were conducted in *IsiXhosa* lasting between an hour to an hour and a half. Recordings were then transcribed verbatim and translated into English by the researcher and resulted in interview transcripts.

3.1.6) Data Analysis:

The Grounded Theory method was used as a method both coding and analyzing the interview transcripts. Grounded Theory Method is defined as "systematic, inductive guidelines for gathering, synthesising, analysing and conceptualising qualitative data to construct theory" (Charmaz, 2001 as cited in Smith, 2003:82). The reason for using Grounded Theory is due to the fact that it minimizes the researcher's possibility of being biased-through adding their own notions, but instead allows the researcher to develop theory that is data-bound, which emanates from the analytic codes and categories emerging from the data, rather than the researcher's own preconceived ideas (Charmaz, 2001 as cited in Smith, 2003; de Vos, Strydom, Fouche & Delpont, 2002).

As far as coding is concerned, the researcher read each interview transcripts line-by-line and jotted comments on the side as an attempt of identifying theoretical categories that emerged from the interview transcripts, bearing in mind the aim of research project. The theoretical categories that emerged from the interviews emanated from comparing the participant's statements between and within the same interview concerning their subjective experiences regarding their psychological challenges associated with disclosing an HIV/AIDS-infected status and how it impacts on their ARV-treatment adherence. According to Charmaz (2001) (as cited in Smith, 2003) comparing participant's experiences and statements that are made during the interview is good practice, as it illustrates that the interviewer is engaging with the data, without necessarily being critical of the participants.

3.1.7) Ethical Consideration:

Participants were debriefed on the nature of the study. The consent form, which was written in *IsiXhosa* so as to ensure participants had a full understanding about what the study entailed, detailed the voluntary nature of participating in the study, as well as participant's right to decline to respond to questions that they felt uncomfortable responding to, as well as withdraw at any particular time if they no longer wished to take part in the study.

As far as confidentiality is concerned, interviewees were informed at the beginning of the interview about their right to use pseudonyms. Allowance was however granted to those participants who wished to use their real names as a manner of claiming ownership of their individual stories. The researcher's contact details were given in case participants had queries with regards to the research study. As a token of appreciation, each participant was gratified an amount of R100, 00 for both their time and willingness to share their narratives.

CHAPTER 4

PARTICIPANTS' BACKGROUND AND RESEARCH FINDINGS

4.1) PARTICIPANTS' BACKGROUND

This chapter focuses on the research findings of this study. It starts off by offering a brief background focusing on the women's demographic information as a form of introducing the participants of this study and goes on to present and discuss the research findings.

Participant 1:

Participant 1 is a 23 year-old and is currently living with her mother and stepfather in Barcelona - an informal settlement in Gugulethu. She grew up in the Eastern Cape with her grandmother but had to move to Cape Town after her grandmother passed away. She is the eldest of three siblings. Her mother works as a domestic two days per week and earns R50 per week. She also receives R180 grant for the last born child. The stepfather is currently unemployed. Participant 1 is currently unemployed and commenced treatment in June 2005.

Participant 2:

Participant 2 is a 50 year-old single parent of two sons aged 22 and 20. Her 20 year-old son is currently serving an 18 year sentence for housebreaking, while her 22 year-old son is looking for employment. She lives in Barcelona with her partner and her 22 year-old son. Her only source of income is through doing people's laundries around where she lives for which she is paid R20/R40. She partially depends on her partner works part-time (i.e. two to three days a week) for financial assistance. Her highest level of education is Standard Eight. She commenced treatment on 16 February this year.

Participant 3:

Participant 3 is a 37 year-old widow with four children. She was born and grew up in Cape Town with her four siblings (i.e. two brothers and two sisters). Her husband passed away in 2000 from an AIDS-related illness. Both her children and her partner do not know that she is living with the virus. Her highest level of education is Standard Eight. She is currently unemployed and depends on the HIV/AIDS disability grant and her second daughter's financial assistance. It has been a year since she has been on treatment.

Participant 4:

Participant 4 is a 47-year single mother of two aged 30 (female) and 27 (male). She originates from the Eastern Cape. Participant 4 lives alone, her daughter is currently in search of a job in the Eastern Cape while her son lives with her mother in the same area as participant 4. She has three brothers and one younger sister who has recently passed on from an HIV-related disease. Participant 4 has not told any of her family members about her status. Her highest level of education is Standard Three and is currently unemployed.

Participant 5:

Participant 5 is a 45 year-old single mother of two sons aged 27 and 16. She originates from the Eastern Cape and was raised by her maternal uncle due to her mother's mental disturbance. She is currently living with her partner and both her sons - (the 27 year-old son is unemployed and the 16 year-old is in Standard Four) to whom she has not told about her HIV-status. She is currently unemployed, no longer receives an HIV/AIDS disability grant and makes a living from selling sweets and chips. Participant 5 was reluctant to disclose her highest level of education. It has been a year since she has been on treatment.

Participant 6:

Participant 6 is a 41 year-old mother of two (an 18 year-old in Standard Nine and an eight year-old in Standard Two). She grew up in the Eastern Cape but is originally from the Northern Cape. She lives with both her sons and is currently unemployed. Her highest level of education is Standard Eight and she makes a living from selling chips and paraffin and receives a monthly support grant of R180 for her second child. She started with ARV-treatment in 2004, and similar to most participants, her family members do not know about her status.

Participant 7:

Participant 5 is a 36 year-old female living in KTC (an informal settlement in Gugulethu). She was born in Cape Town in Gugulethu (a township in Cape Town). The seventh out of eight siblings, participant 7 left school while she was doing Standard Six. She is currently living with her partner in KTC, is unemployed and not receiving an HIV/AIDS disability grant due to her escalated CD 4 count. Their source of income comes from her partner's disability grant and from what her partner earns by mending shoes. She has been on treatment for three years and has refrained from sharing this information with her family.

Participant 8:

Participant 8 is a 32 year-old single mother of two. She is currently living with both her sons aged eleven and six. Participant 8 has never met her biological parents but the woman whom she refers to her as "mama" passed away in 2000. Nomhle's highest level of education is Standard Eight. She is currently unemployed and is receiving an HIV/AIDS disability grant and each of her sons receives a R180 grant. She states that she joins savings groups as a means of saving money. Participant 8 has been on treatment for two years.

Participant 9:

Participant 9 is a 33 year old single mother of two from the Eastern Cape. She is the eldest of six siblings. Participant 9's highest level of education is Standard Six. She is currently living with her two children, is unemployed and depends on the HIV/AIDS disability grant. Her partner is also HIV-positive and she views this as a blessing because both herself and her partner advise each other on HIV/AIDS-related matters. She has not disclosed to anyone else besides her neighbour, her boyfriend and her support group. She has been on treatment for two years.

Participant 10:

Participant 10 is a 46 year-old mother of three who grew up in the Eastern Cape. Together with her four siblings they were raised by both their parents. Both her children managed to finish Matric but because of financial constraints, could not continue with their studies, her eldest daughter lives in Port Elizabeth and is looking for job while her son has a part-time job. Her youngest daughter lives with her mother in the Eastern Cape. Participant 10's highest level of education is Standard Six. She is financially dependent on her son with whom she lives with. It has been two years since she has been on treatment and her sister whom she does not live with is the only person (amongst her family members) to whom she has disclosed her HIV-status to.

4.2) RESEARCH FINDINGS

From an analysis of the interview transcripts, four themes emerged to explain the women's subjective experiences with regard to the psychological challenges they faced associated with disclosing their HIV/AIDS-infected status and the impact of adhering to an ARV-treatment schedule. When quoting the ten women in the discussion below, they will be referred to as 'participants' rather than using personal names, to ensure anonymity. Pseudonyms are used in cases whereby names appear. The themes that emerged were as follows:

<u>Themes</u>	<u>Description of themes</u>
<i>1. "FEAR OF NEGATIVE OUTCOMES"</i>	Refers to the possible adverse consequences participants dread would result from the disclosure of their HIV/AIDS-infected status.
<i>2. "DISGUIISING AN HIV-POSITIVE STATUS"</i>	Refers to the various 'less stigmatized' illnesses participants pretend to be ailing from as a strategy to conceal an HIV-positive diagnosis.
<i>3. "ARV-TREATMENT TAKING STRATEGIES"</i>	Refers to the various treatment-taking strategies participants employ when taking ARV- treatment in the presence of those they had not disclosed to.
<i>4. "ARV- TREATMENT ADHERENCE AFTER DISCLOSURE"</i>	Refers to the participants' patterns of taking medication and adhering to the treatment schedule after disclosing their HIV/AIDS-infected status to treatment assistants or relevant others.

4.2.1) FEAR OF NEGATIVE OUTCOMES

All the women in this study found that, disclosing their HIV/AIDS-infected status was not only a matter of degree but it varied from person to person; in other words, participants chose to disclose their status to certain relevant individuals in their lives, while keeping the same information hidden from other relevant others. The results from this study highlight the various fears that participants anticipated they would experience once they disclosed their HIV/AIDS-infected status. These included:

- a) Fear of exacerbating the illness of already ailing elderly parents;
- b) Fear of being accused of promiscuity;
- c) Fear of being rejected by the partner and
- d) Fear of losing economic support.

Each of these will be discussed below.

a) Fear of exacerbating the illness of already ailing elderly parent:

Results show a common fear by participants to disclose their HIV/AIDS-infected status to their mothers. The reason given by participants was the belief that, if their elderly mothers knew that the participants were infected, it would aggravate the deterioration of their mothers' health, and might at worst even lead to their death.

Participant 4 stated:

I said: No I am going to remain silent so long, because my mother is old and such news may lead to her death so I think it is best if I keep it to myself. I worry what this might do to her. The thing is people tend to think of this as a killer disease. So I fear that if I tell her...she would be the one who dies instead. (Participant 4)

Similar views concerning the deadly harm such information could cause her mother were expressed by Participant 9 who asserted:

I thought this is going to be difficult because my mother is not well, so if I were to tell her this...I would be killing her so I thought it is best for me to keep it to myself. (Participant 9)

From the above excerpts, it can be deduced that participants considered non-disclosure as a means of protecting their mothers, who were sometimes elderly, sometimes ill themselves, and sometimes both elderly and ill, from the possible adverse impact, which the knowledge of such information might cause. The negative connotations of being infected with HIV/AIDS clearly contribute to their reluctance to admit that they are infected. Furthermore, as infection with HIV/AIDS is so closely associated with death, participants are reluctant to share such information with their mothers. Not only do participants fear that they might exacerbate the ill-health of their parents - or even cause their premature death, but they are also afraid that they would always feel guilty for causing such harm to their mothers. The women in this study come from traditional backgrounds, in which it is regarded as the responsibility of a daughter to look after her mother or to be concerned about her mother's well-being. Their fear of causing harm to their mothers overwhelmed the participants with feelings of guilt and shame for failing to be 'good daughters.' Furthermore, they felt that they had engaged in 'bad behaviour,' which led them to contract the virus - or that their families would think this. In view of all these factors, participants were likely to refrain from sharing the news of their HIV/AIDS diagnosis with their mothers.

b) Fear of being accused of promiscuity:

The fear of being accused of having multiple sexual partners served as an additional reason why some of the participants hesitated disclosing an HIV/AIDS-infected status.

Participant 9 maintained:

I did not want to tell my other siblings I was scared. The thing is people have a tendency of not understanding how HIV gets transmitted. So now what happens is that they think you had a lot of partners...so I thought I should not make them aware of my status. (Participant 9)

A similar opinion was held by Participant 6 who asserted:

The reason for maintaining silence is that HIV-negative people, you people...you have a tendency of thinking that once a person is HIV-positive, she has been sleeping around, we are being immoral. For instance, they would say: It serves her right she has been sleeping around. (Participant 6)

Participant 4 stated:

I am really not a friend's person. I do have a friend at church, but that is just where we meet and nowhere else. No, she (referring to friend) does not know about my status. The thing is I go to Zion and it is a church full of illiterate people so they would not understand. They would reject me, they would not want anything to do with me nor my children. (Participant 4)

Participant 7 held a similar view with regard to being reluctant to disclose her HIV/AIDS status to her church-going friend

The thing is... it is difficult to disclose to church-going people. It is very difficult to say: Do you know that I am sick so and so? Because at church we are told that we should not date, so once you disclose about this they would just know: Yho! so and so is a sinner, so that is why I thought I should not share with them. (Participant 7)

The above excerpts highlight the negative stereotypes - social and religious, which lead to participants being reluctant or fearful of disclosing their HIV/AIDS-infected status. For instance, the first two participants feared people labelling them as 'sexually promiscuous,' whereas the last participant feared that her fellow church members would find out that she had been sexually active. Campaigns such as the Abstain Be faithful Condomise (ABC) Campaign and virginity testing, which are aimed at combating the spread of HIV/AIDS, ironically help to feed the negative stereotypes concerning the transmission of the epidemic.

As already explained in the literature review, the ABC Campaign implied that, in order to avoid HIV transmission, individuals had to abstain; be faithful (i.e. have one sexual partner), or use a condom. This implies that individuals who are infected have failed to obey the basic rules of avoiding contracting HIV/AIDS, as it puts the sole

responsibility of avoiding HIV/AIDS on the individual. Thus, refraining from disclosing one's HIV/AIDS-infected status was thus considered by participants as a form of avoiding an 'identity confirmation' of being seen as individuals who have transgressed or deliberately ignored the rules of avoiding HIV/AIDS-infection after being informed of these. This indirectly implies that they have not abstained from sexual intercourse, that they have had multiple sexual partners, and that they have engaged in unprotected sexual intercourse, i.e. they have failed using condoms.

In addition, the cultural practice of virginity testing as an alternative campaign to combat HIV/AIDS transmission has also encouraged the negative stereotypes concerning HIV/AIDS transmission, as it places more focus on the sexuality of females than that of males: this means that female HIV/AIDS-infection is more stigmatised than that of males. For instance, although males do also undergo virginity testing, it only applies to a small percentage of males, far less so than females (Buthelezi, 2000). The significance of virginity testing is that it is intended to instill characteristics such as 'good behaviour; purity; innocence etc..' however such characteristics are only considered worthy when they are associated with women. According to Walker, Reid and Cornell (2004), the aspiration to be associated with such characteristics is so pervasive amongst females, that their fear of being associated with sexual promiscuity is far more intense than among males. Walker et al. (2004) maintain that a large part of this is partly due to the subordinate role accorded to women by society: whereas having multiple sexual partners signifies 'masculinity' amongst males, women with multiple sexual partners are viewed with contempt and are negatively labelled and are more likely to be blamed and seen as deserving to be HIV/AIDS-infected.

Effectively, then, such campaigns and their implications play a role in the participants' decision not to disclose their HIV/AIDS-infected status: as participants would be 'confirming' a deviant character of 'immorality; loss of innocence and sexual indulgence' if they disclosed their status. They chose rather to remain silent, as this offered them protection against the negative connotations associated with an HIV/AIDS-infected status. This is also because, through female sexuality surveillance, transmission is portrayed as a female responsibility. The irony of virginity testing is that, although it is aimed at combating the HIV/AIDS epidemic, it

has the potential of having the opposite effect (Murphy, 1999). Murphy argues that, because girls who pass the 'virginity test' (i.e. girls who are 'confirmed' virgins) are marked with emblems on their foreheads to symbolise their 'purity,' their chances of being raped by HIV/AIDS-infected males who believe that intercourse with a virgin cures the HI- virus. Clearly this is contrary to the aim of the campaign.

The results of this study further showed that the fear of being viewed as sexually promiscuous was linked to participants' religion affiliation. Participants believed that their fellow church members lacked the educational background that could help them understand the dynamics of HIV/AIDS transmission. It is thus necessary to consider sexuality, in the context of religious beliefs, in order to make sense of participants' reluctance to disclose their HIV/AIDS-infected status within a religious context.

Religion puts great emphasis on the purity of the body, which is expressed in sayings, such as "The body should not be used for sexual immorality, but to serve the Lord" (Corinthians, 6: 19-20). However, it is females that are expected to be 'pure,' 'virginal' and dedicated to only one male partner. Biblical examples of women, such as Mary mother of Jesus illustrate the expectation of women's 'purity.' It is interesting, though, that the same religious laws that discourage multiple partnership amongst females do not prohibit males from doing the same; instead, multiple partnership are considered acceptable for males: "A man can marry an infinite amount of women without any limits to how many he can marry" (Exodus 21:10). This is biblically discouraged amongst females: "A married woman, for example, is bound by the law to her husband as long as he lives. So then if, she lives with another man while her husband is alive, she shall be called an adulteress, but if her husband dies, she is legally a free woman and does not commit adultery if she marries another man" (Romans 7:3). These biblical texts are taken seriously by believers in the bible, and influence the manner in which sexually active women who contract HIV are perceived.

This is similar to the cultural tradition of virginity testing, the reasons above (viz. the church's association of 'virginity' with 'goodness,' and the belief that multiple partnerships are appropriate for males but not for females contribute to participants being hesitant to disclose their HIV/AIDS-infected status). This is particularly the case in a religious context or in relationships based on religious foundations, because

these contribute to producing religiously-induced guilt. The reason for this is that individuals who are HIV/AIDS-infected are often labelled negatively and are considered 'bad' or 'immoral' for failing to maintain their 'purity.' Participants in this study, who were not married, were afraid to be seen in a negative light as 'impure, promiscuous' and therefore as 'sinners' who have engaged in illegitimate sexual intercourse. Not only were they afraid that they would be regarded as 'sinners,' but also that their fellow church members would view them as 'deserving' the 'punishment' of HIV infection, because they had gone against religious 'moral' laws. The above commonly held religious ideologies seem to be important factors that contribute to participant's fear to disclose an HIV/AIDS-infected status.

c) Fear of being rejected by the partner:

The fear of being rejected was another reason why some participants could not disclose to their partners and family members that they were HIV-positive. Some of them had personally experienced such rejection or had observed others being rejected after they disclosed their status. Participant 10's previous partner, for example, had left her immediately after he had promised never to do so. The participant describes the experience as having been so painful that she had not wanted to disclose her status to her current partner, fearing that he too would leave. She explained:

My boyfriend left me directly after I disclosed to him. That was one of the reasons that led me to lose so much hope. I had lost hope. I thought I was just being honest by telling him, only to find out that I was chasing him away. Oh! at first we used to joke about it and say to each other: You know what Buli even if one of us could be HIV, I do not think that would cause us to break up, because if one has it, the other one definitely has it. We used to joke about that. I never knew it would happen, we had a good time, but after disclosing about it, he is the one who left me...I was heartbroken. The reason why I am not telling him (referring to current partner) about my status is that I fear to repeat what happened in the past. He does not know about my status, but we do condomize, we do condomize. (Participant 10)

The same fear was also expressed by Participant 8:

I just cannot remember this other film that Portia was acting in, so what she did was disclose to her boyfriend after sleeping with him and after using a condom, so after disclosing about her status her boyfriend swore at her, picked his clothes, slammed the doors and that was the end of their relationship, after that I told myself that disclosing an HIV/AIDS-infected status is not ideal...especially because you disclose and then you end up losing your boyfriend so I think it is better for one to not disclose to their partners and just use a condom. (Participant 8)

The above two participants were thus fearful that their partners would reject them after they had disclosed their HIV/AIDS status to them. This was based on their own prior experiences of rejection, as well as on the negative portrayal of HIV/AIDS disclosure in the media. They were thus reluctant to share such information with their partners. Instead, participants believed that, even if they would try to avoid transmitting the infection to their partners, whether it was through disclosing their HIV/AIDS-infected status or encouraging the use of a condom, such efforts were not appreciated by their partners. Instead, they expressed the belief that it was inevitable for them to be rejected by their partners.

Part of the participant's reluctance to experience such rejection emanates from the stigma associated with being rejected by a male partner in heterosexual relationships. It should be borne in mind that the participants of this study came from a cultural context, which encourage heterosexual partnerships or having a marriage or partner, and which furthermore associate female 'wholeness,' 'validity' or 'completeness' with having a male partner. As a result, women with partners are accorded respect, whereas women who are left by their partners are likely to be considered 'failures', or as 'unable to keep a man,' and for such reasons are deemed 'worthless.' According to Glanz and Spiegel (1996), the shame such women feel after they have been left by their partners emanates from the social roles associated with women as being 'nurturers' within their family systems and society. This belief leads to the gendered role of women being seen as the ones who are responsible for the welfare of the relationship. Thus, if a woman remains with her partner, she is accorded 'respect,' whereas a woman whose relationship dissolves, is not. Studies by Ezeokana (1999); and; Van Schalkwyk (2005) have shown that there is a tendency for women to have negative feelings, such as a loss of self-worth, sadness, and a loss of their socially

constructed self after the termination of their relationships. From participants' comments, it can be deduced that they remained silent for various interrelated reasons: to avoid being stigmatised for being HIV/AIDS-infected, to prevent being rejected by their partner; to avoid feelings of loss and worthlessness after being rejected by their partners.

In addition to these reasons, Participants 2 and 10 also feared that their family members' misconceptions about HIV/AIDS would lead to them being rejected if they confided in them.

Participant 10 maintained:

My fear is that my family would exclude me. I fear that I would repulse them, perhaps they would feel as if something has changed. Really, nothing has changed. I am still the same person. I worry that I would repulse them, they would not accept me and keep their distance from me, so those are the reasons...at least that is what I worry will happen once I disclose. (Participant 10)

Participant 2 asserted:

My brother would be disgusted. The thing is other people tend to think this thing is easily transmittable this thing cannot be transmitted by a spoon or whatever. He will think that this thing is easily transmittable...he will think that this thing is contagious. He would not understand. For instance, he would think: Yes, she is on treatment, but it is contagious. You would be explaining to him and he would be thinking "um-um" (i.e. no). I don't want anything to do with her. I am talking from experience...the HIV virus...now that I have it, because what we, HIV-negative people used to think then was that we would never be able to sit next to an HIV-positive person, we used to think that it was possible for it to be transmitted via talking, sharing a spoon and all of that... so those are the kinds of things I took into consideration. For instance, we used to even fear using the toilet. We feared that they might have been used by an HIV-positive person, it would seem as if you would contract it, those kinds of things. (Participant 2)

The above statements highlight the misconceptions that exist about the transmission of HIV/AIDS. Participants feared that their families would reject them because of these, and this discouraged them from sharing the information with some of their family members. Families are ideally seen as support structures that provide 'nurturing conditions' for members, such as empathy, support, affection and loyalty. In other words, families are ideally supposed to be structures within which individuals feel safe enough to share any challenges they are face with. Thus, the possibility that one could be rejected by the same institution that ideally ought to be loyal irrespective of the challenges they are faced with, shatters the assumptions and preconceptions that are commonly held about the family unit. Some of the participants were familiar (either through personal experience or observation) with scenarios of rejection, the possibility or likelihood that they themselves might be ostracised by their families too, would have encouraged them to remain silent about their status.

Despite the possibility of experiencing rejection from one's family, the ARV policy encourages HIV/AIDS-infected individuals to disclose their status in particular to the family members they live with in order to be able to access treatment. On the one hand, the policy's intentions are fair, as it is believed that family members would assist or work hand-in-hand with loved ones who are receiving treatment. It was also believed that, by being informed about the reason of their loved one's ill-health, they would be more likely to offer support and encourage them to adhere to their treatment, thereby ensuring that it becomes effective. It was also felt that supportive and informed family members would be more likely to present their loved ones to health officials should any complications surface whilst they are receiving ARV medication.

On the other hand, the policy that requires disclosure to family members has failed to acknowledge that, this is different from tuberculosis (TB) on which the policy of disclosing to a family member derives from. The stigma surrounding HIV/AIDS makes it difficult for HIV/AIDS-infected individuals to disclose their status. The HIV disclosure policy has been too idealistic in assuming that family members of HIV/AIDS-infected individuals would automatically offer them support. Instead, various studies, as well as the real-life experiences of the participants, have highlighted the cruel effects of abandonment after disclosing their HIV/AIDS-infected

status to family members (Garcia & Cote (2003); Mugavero & Hicks (2004). Participants might not have prepared themselves or their loved ones before sharing such information. However as the ARV policy obliges an HIV/AIDS-infected individual to disclose his or her status to a family member one cohabits with, participants somehow felt pressurised to disclose to family members, but were afraid of the consequences, such as being rejected by their families.

d) Fear of losing economic support:

The fear that they would lose economic support if their partners or families rejected them, served as a further reason why some of the participants refrained from disclosing their HIV/AIDS-infected status.

In that regard, Participant 2 explained:

What I was avoiding is..., I thought if I were to disclose to him (pause) he would abandon me. Do bear in mind that I am not working and I am thin on top of that. At least the R50,-00 that R50,-00 that he brings home, even if it is only once per week, it does play a role. So I thought: Hey! He will abandon me. (Participant 2)

Similar concerns were expressed by Participant 5:

The thing is that I am not working, I do not receive any form of income so I was worried that I would struggle if he had to leave me. I was also worried because he pays my son's school fees...I worried that I would struggle if he were to leave. (Participant 5)

These women's statements' highlight the financial challenges they would have to face if their partners rejected them after disclosing their HIV/AIDS status. Shabodien (2005) found that females who admitted to their male partners that they were HIV/AIDS-infected status risked being abandoned by them, which could result in impoverishment because females are more disadvantaged economically than males. The participants of the study conducted by Shabodien (2005) like the women who participated in this study, came from economically disadvantaged backgrounds, and their highest level of education ranged from Standard Three to Standard Eight. Furthermore, they were all unemployed and some women depended on the HIV/AIDS

disability grant and/or a monthly income ranging from R50, 00 per week to R180, 00 per month from the irregular domestic chores some participants performed for individuals within their neighbourhoods or child grant. The disability grant, which some participants solely depended on, would be stopped once their CD4 count escalated, as this was a sign that infected individual's state of health was improving and were thus capable of seeking employment. This is compared to when their CD4 count was low and were considered as being unable to be employed or work (Simchowitz, 2004). The cessation of the disability grant however has the potential of jeopardizing the effectiveness of ARV treatment because medication ought to be taken with food. Thus if they were no longer receiving the grant and if their male partner simultaneously no longer supported them financially, then they would be unable to afford food. Some participants mentioned going for days without food. This is another serious challenge, because the treatment not only increases one's appetite, but also works optimally when the medication is taken with food.

The economic disadvantages that women face also have implications with regard to the management of their sexuality. For instance, it may increase their risk of HIV/AIDS-infection and re-infection or cause them to succumb to violent partners. Some of the participants in this study mentioned that, although they were aware that their partners had extra-marital affairs, they could not leave their partners due to cultural and economic reasons. Also, almost all the participants in this study mentioned that they had been beaten by their partners, but that economic reasons forced them to remain within such abusive relationships. The economic instability these women faced had further implications as far as HIV/AIDS re-infection is concerned. For instance, the association of masculinity with having frequent sexual intercourse with numerous partners and non-condom use, places women at a higher risk of infection or re-infection.

Although female condoms are available, women's low economic status means that they are not able to be assertive with regard to using such condoms; in addition, it is often considered taboo among their communities for women to insert female condoms. Thus, given their fear of financial challenges and abandonment by their partners if they admitted that they were HIV-positive, participants tended to succumb to their partner's violent behaviours. They did so to ensure the welfare and survival of

their families, and particularly the education of their children; their fears in this regard were exacerbated by the realisation that leaving their children without resources due to the possibility of a sudden death would have a devastating impact on their children's future. By remaining silent about their HIV/AIDS status, then, participants felt that they were protecting themselves against rejection, abandonment and loss of financial support, thus ensuring that they could make the minimal provision for the welfare and survival of their families.

4.2.2) DISGUIISING AN HIV-POSITIVE STATUS

In addition to keeping their HIV/AIDS status secret from their male partners and from the family members they lived with, the participants in this study pretended to be suffering from a variety of illnesses to justify taking their treatment and to keep an HIV/AIDS-infected status secret. Although their significant others were sometimes aware that participants were receiving treatment, the participants lied about the reasons for taking the treatment. Justifications for taking treatment included the following:

I pretend as if I am getting bone treatment, I pretend as if I am taking my bone treatment, because the doctor told me that I have bone problems. (Participant 1)

Participant 8 stated:

My brother's girlfriend always used to ask: Haybo! Thoko! What are these tablets that you are forever taking at 9? I told her: Hayi (i.e. no) I suffer from sugar diabetes, the doctor said I have sugar diabetes so I am taking sugar diabetes treatment. That was the end of our discussion. (Participant 8)

Participant 7 explained:

They just see me taking tablets. They do ask and I tell them that they are for asthma. I do not want them to know about my status. (Participant 7)

Participant 3 asserted:

On the first day she asked me: What are the tablets for? And I said: They are for T.B. I have chest problem. (Participant 3)

Participant 5, in contrast did not justify her treatment taking by faking a certain disease, but instead maintained that the treatment was for health-boosting purposes. She stated:

I told him that the treatment I am taking is just for boosting my immune system. He does not really know what they are for...as a result he also sometimes reminds me to take them in the evening. (Participant 5)

In contrast to the above participants, Participants 6 and 9 did not necessarily lie about the reasons for taking medication. Since they had been diagnosed with T.B., the family members knew they were taking T.B. medication. But often the T.B. diagnosis was part of the HIV/AIDS symptomatic picture, and the T.B. treatment was essential before they started the ARV treatment regimen. However, when they switched to ARV's, participants simply kept this to themselves.

Participant 6 asserted:

They do however know that I had T.B. so I never really told them what they are for, so they still think I am taking my T.B. treatment. No, all they know is that I am on T.B. treatment that is all. (Participant 6)

The same sentiments were echoed by Participant 9, who had also been on T.B. treatment:

Hey! I will probably tell them after a long time, because I worry that if I tell my children at such an early age...won't they worry that: Hey! mama is HIV? So that is what I am concerned about. I do not want to tell them as yet, because I think they are still too young. They just knew that I had T.B., but now they can see that I am okay and I tell them T.B. is curable, I am fine now. (Participant 9)

In contrast to the rest of the participants, Participant 4 does not name the illness for which she is taking treatment. She explained:

My mother never knew what the tablets were for, she just sees me taking them. She does not. I just told her they would cure the sickness that I have, I have never told her what the sickness is. (Participant 4)

From the above statements, it is evident that participants generally did not tell the truth about the medication they were taking, preferring to say it was for various other illnesses instead of HIV/AIDS. The common feature of the illnesses presented by the participants is that they are all less stigmatised socially than HIV/AIDS. Goffman (1963: 73) termed such form of behaviour or coping mechanism as “passing.” According to Goffman, the practice of “passing” entails the adaptation of various forms of behaviour in an attempt to conceal the stigmatising disease. In this study, “passing” involved participants attributing their ARV treatment to less stigmatized illnesses, such as arthritis; T.B. and sugar diabetes. The sexual nature of HIV/AIDS-transmission may also have played an important role in participants’ reluctance to disclose their status, as none of the illnesses mentioned by participants were sexually transmitted, and thus less stigmatized than the case is for HIV/AIDS.

Goffman (1963) suggested that the reason for “passing” was to maintain ‘usual/normal’ interactions with others. It could be said therefore that participants pretended to suffer from other less stigmatising illnesses rather than HIV/AIDS in an attempt to maintain ‘usual’ or ‘normal’ relationships with their loved ones. The very real fear that they might be discriminated against if they disclosed their status led participants to fake less stigmatized illnesses in order to ensure that participants kept relating with them as they had before they had become infected or before they had found out about their status.

4.2.3) ARV-TREATMENT TAKING STRATEGIES

The majority of the participants, i.e. nine out of ten (with the exception of the one who had disclosed her status before commencing with ARV-treatment) had not disclosed their HIV/AIDS-infected status or the real reason behind taking ARV-treatment to those with whom they were cohabiting. In addition to attributing treatment taking to various illnesses, except HIV/AIDS, they consequently made a conscious decision to take their ARV-treatment in secret to further ensure that their HIV-positive status was kept a secret.

The participants were aware of the fact that merely misinforming significant others and pretending to suffer from less stigmatized illnesses was not enough to mask an HIV-positive status. They also had to employ certain tactics when taking treatment to ensure that their status remained a secret. The results of this study revealed such participants always excused themselves and administered treatment in a different room if family members (to whom they had not disclosed to) happened to be present. Participant 2 stated:

I have a two-roomed house, if he is in the dining room, I would take my tablets in the bedroom and if he is in the bedroom, I will take my tablets in the dining room. I would take these tablets in whichever room at home as long as he was not in the same room. I was trying to ensure that he never finds out. (Participant 2)

A similar description was given by Participant 3 when she had to take her ARV treatment while people to whom she had not disclosed, happened to be around. She asserted:

The thing is our houses are four-roomed, so what would happen is that, they would be in the TV room, so what would happens is that they would be in the TV room. So I come from the dining room where the people are sitting, go to the bedroom, take out my pills and hold them in my hand and then go to the kitchen that is where I will have them, the people would be in the dining room. (Participant 3)

In contrast to the two participants who take treatment in a different room in the house, Participants 4 and 7 vacated the house or building completely in order to take their medication:

Participant 4 explained:

I take my bag and go outside with it, and take my tablets once I am outside. Both in the morning and evening, whenever I have to take my tablets, because at home... there are two taps at home. So what I would do is go out, they would be in my hand at the time, go outside and take them there. (Participant 4)

Participant 7 gave a similar explanation of what happens when she has to take her medication when she is in the presence of people to whom she had not disclosed:

At church when we have night vigils I would have to take my treatment at nine o'clock, my tablets would be wrapped in plastic. I would leave church for a few minutes and then go back after that. (Participant 7)

For Participant 8, excusing herself to take her medication meant going through the daily pretence of using the outside toilet every morning at nine o'clock. She maintained:

It was better in the morning because I would just take them outside. I would pretend as if I am going to the toilet, our toilet is outside. I would pretend as if I am going to the toilet and I would take them there. (Participant 8)

Participant 8 expressed concern about the impact of this hiding behavior on adherence. For instance, although she had a place to store her medication, it was not always possible for her to access and to take it at the prescribed time. She explained:

I used to keep them in my wardrobe so what would happen is that I would take them out of the wardrobe. The house is small now, there was only one bedroom. It was difficult because you would find that sometimes there were films they wanted to watch in the evenings and I would have to take my treatment at the same time, and the tablets are quite loud (due to the rattling sound they make) and it does not matter how you handle them. I ended up taking the tablets at 10 when I was sure that people were sleeping. What happened was that I was not carefully adhering to the treatment times and the doctor had questions. (Participant 8)

The above interview excerpts highlight the various strategies employed by participants when they had to take ARV-treatment in the presence of relevant others whom they had not disclosed their HIV/AIDS status. Although participants may have been successful in pretending to suffer from various illnesses to camouflage their HIV/AIDS status, they also considered it necessary to be secretive about taking their ARV-treatment, particularly when surrounded by those to whom they had not disclosed to. Such tactics were, however, anxiety provoking for those participants who employed them: they continuously had to be cautious of where they took their medication, as well as avoid being watched or seen. For example, the comment made by Participant 8 illustrates the impact that the lack of privacy could have on treatment

adherence. The presence of Participant 8's family members in the room where she kept her treatment meant that she had to refrain from adhering to her time schedule for taking the medication. Such challenges and specifically lack of privacy disrupted the treatment of their illness, and would potentially jeopardise the efficacy of the medication. Moreover participants believed that if they were always seen taking medication, they might be interrogated and questioned all the time, which might lead to them accidentally giving away the real reason for taking this medication.

Three participants of this study employed a different approach to taking their ARV's. For instance, in contrast to the participants who only took their medication in the absence of individuals they lived with because they had not disclosed the real reason for doing so, these participants (who had also lied about the reason for taking the medication), simply went ahead and took their treatment, even if those they were living with were present. They had made up an illness to explain the medication, and this made it possible for them to take the treatment openly.

Participant 10 asserted:

I do not hide them. I just put them wherever, even now...they are in a plastic bag even now. I put them wherever, take them when it is time to do so even if they are around (referring to family members) and put them back again. (Participant 10)

Participant 3 expressed similar views:

I do not hide them. I just put them there and as a result send one of them to fetch. I tell them: Please bring my tablets and I take them. (Participant 3)

Participant 1 explained:

She sees me take them. I take them normally, I never skip a day. She sometimes gives me praises and says: You see, the bone-treatment is improving your health.

(Participant 1)

As excerpts show, not disclosing an HIV/AIDS-infected status to individuals one cohabited with appeared to be useful and beneficial for participants in terms of adhering to treatment. The fact that participants pretended to have various other

illnesses to hide the fact that they were HIV-infected meant, that they did not need to hide their medication, and that they were able to take it in the presence of others when it was time to do so. As the members of their households did not know what ARV-treatment looked like, it meant that participants did not have to hide it. This ensured that participants adhered to their ARV-regimen.

The results further highlighted a subtle kind of silence associated with treatment taking.

Participant 6 stated:

I just put my Bactrim and Vitamin Beco wherever, but I always hide my ARV's. I put them in different containers, they (referring to children) also do not know about this. If I am going somewhere they would ask: Are you going somewhere today? And I tell them: No, I am not going anywhere, and they would say: If you are leaving, do not forget your treatment. Since I told you that I do not have a T.V. so they do not know what they are meant for. They would only know about them once they see them on T.V. I always hide my ARV's and take them when the time is right. (Participant 6)

Although she could take her treatment in the presence of her children who could in turn remind her to take her treatment, Participant 6 continued to remain silent about her status by changing the original containers of her HIV-related medication. Participant 6's comment illustrates that the risk of one's HIV/AIDS-infected status being discovered encouraged extra caution around the storage of ARV treatment. This was also a subtle way of ensuring that their HIV/AIDS status remained secret.

The results furthermore show that, although participants may have been successful in concealing from their families that they were receiving ARV-treatment, their family members did sometimes become suspicious.

For instance, Participant 4 stated:

My children don't know, but they are suspicious a bit. I get this from when they talk, they would not necessarily be talking about me. For instance, every time I take my treatment, they would say: We heard that so and so had this accident and she is on

treatment. And I would tell them: The containers are the same, but what is inside is totally different. (Participant 4)

The family members of Participants expressed their suspicions in the following manner:

They asked me: What is happening Thoko, everyday at nine o'clock you are just occupied... even in the morning. You never miss nine o'clock in the morning. I told them: I am already used to going to the toilet at nine o'clock. (Participant 8)

The statements of these two participants reveal that family members did take note of their behaviours and as a result interrogated them about it. However, since they wanted to keep this information hidden from their loved ones, they downplayed their suspicions by giving a different reason and justification for the medication in the containers and excusing their new habit of using the toilet at a specific time. By downplaying their family members' suspicions through coming up with excuses for their acts, they sought to ensure that family members were kept in the dark about their HIV/AIDS-positive status.

The results further showed that attempts to hide one's HIV/AIDS status went beyond just taking treatment in the absence of relevant others and/or hiding the real reason for taking treatment. It extended to: a) Collecting treatment at a different location although treatment was available in one's area of residence, and b) Deceiving significant others about the purpose of a support group.

Participant 6 mentioned:

I get it from Crossroads. The reason I fetch it in Crossroads is that I dread being known, seeing that I have not disclosed. (Participant 6)

Participant 8 stated:

Actually there is a place in Gugulethu, but I choose not to take it there. People do not know my status there that is why I chose Crossroads. (Participant 8)

Participant 7 expressed:

I live in Gugulethu, but I take it in Crossroads. The reason I take it in Crossroads is that I dread being known, seeing that I have not disclosed. (Participant 7)

Participant 5 explained:

I take my treatment in Groote Schuur to just avoid talks. I have not disclosed that is why I am taking my treatment there. (Participant 5)

The above interview shows that the need to keep one's HIV/AIDS status secret was so great that participants would rather opt to collect treatment in a neighbourhood further away where they were not known than in their own neighbourhood. The official treatment collection sites for ARV treatment were either situated in the same yard as the clinic, with the specific site being set aside for the collection of ARV- medication, or located outside the clinic. Patients with different ailments would go to the same clinic but the point of collection for their different treatments would differ. In this way, participants' reasons for visiting the medicine collection sites would be obvious when they collected their medication. This is clearly stigmatising and contributes to participants seeking treatment at different sites rather than in their own residential areas. Collecting treatment in their own neighbourhood would potentially reveal their HIV-positive status since others would know or suspect their reasons for attending the clinic ARV site. It should be borne in mind that the clinics from which individuals collected their treatment were not only visited by individuals who were HIV-infected, but individuals with different ailments were often accompanied by their friends. Sites of medicine collection varied: sometimes there was a different building for collecting HIV-treatment; at other times, participants would collect their medication at different sections in the same building which would risk exposing what treatment they were receiving.

As these clinics were usually within their own residential area, participants feared that they might accidentally meet with familiar people who could then know or suspect about their status. They feared public knowledge about their HIV-infected status. They feared that their family members or significant others would find out about their HIV-positive status. The main reason given by participants for dreading the

information of their HIV/AIDS-infected status to be disseminated by other individuals (even if they did intend to share this information with their loved ones), was they felt that the dissemination of such information by others would not take place in a 'sensitive' manner. A 'sensitive' manner of delivering the news entailed 'preparing' significant others before telling them. This preparation would take the form of asking questions (e.g. "How would you react if you were to find out I am HIV positive?"), encouraging them to watch HIV/AIDS-related programs and convincing others that HIV is not a 'bad' illness. It could also include planning a meal and inviting family members, and then breaking the news of being HIV/AIDS-infected to them. Participants believed that there were channels that should be followed before disclosing their HIV/AIDS status. In this way, there was a greater chance that their significant others would not react negatively or 'overreact,' than if the information had been given to them without preparing them first. Thus, to avoid being spotted by others at clinics, and the information about their HIV-positive status reaching family members prematurely, participants often collected treatment from different sites.

Additionally, they try to give different explanations concerning the real purpose of HIV-positive support groups, as a form of being discreet about an HIV/AIDS diagnosis. HIV/AIDS support groups are made up of individuals living with HIV/AIDS and their aim is to offer an empathetic platform where individuals are educated about the virus and taught how to take better care of themselves. As an initiative of encouraging the consumption of healthy food and poverty alleviation, Woolworths Food donated food to *Luvuyolwethu* Organization, which was distributed amongst its clients. Participants gave various false reasons to their relevant others for attending a support group:

She asked: Where does this food come from? And I said: No I get the food from this other committee. I said I wanted to join while I don't have a job yet, so I finally went to register. (Participant 1)

Similarly, Participant 6 stated:

They know that there is something I do in New Cross. I tell them we have a woman's committee. I don't say it is a support group. I just say to them it is a woman's committee. I tell them it is called Bambanani and that it is a woman's committee. I

also tell them that the people we are working for are considerate enough to give us food to eat. (Participant 6)

The above statements show that participants formulated stories to explain where they had obtained the food they brought home. Neither of the two participants mention the concept 'support group' when they tell their significant others where they had collected their food. Although support groups could and do exist for various ailments, the epidemic of HIV/AIDS has led to the widespread emergence of such support groups, and thus attendance at these has come to be synonymous with being HIV/AIDS-infected. Participants thus deliberately refrained from using the concept 'support group,' as it would indirectly reveal that they were HIV/AIDS-infected. For this reason, participants thought it was safer to pretend that they had obtained the food from committees rather than from support groups doing so, did not automatically give away their HIV/AIDS-status.

4.2.4) ARV-TREATMENT ADHERENCE AFTER DISCLOSURE

The results show that the routine of taking treatment was made easier and they were more likely to adhere to treatment in cases whereby participants took treatment in the presence of the relevant others they had disclosed to. Participant 2 explained:

Before Participant 2 disclosed her HIV/AIDS status, she took her medication in a secretive manner:

I have a two-roomed house, if he is in the dining room, I would take my tablets and have them in the bedroom and if he is in the bedroom, I will take them in the dining room. I would take these tablets in whichever room at home as long as he was not in the same room...I was trying to ensure that he never finds out. (Participant 2)

After disclosing the reason for her treatment, however, this changed completely. She states:

I take them freely, you see...my house...kukwangenani (people are always welcome). It is always fun to be there, if bhut Xola's...friends... happen to be around at 8 o'clock, what I do is take my yellow bag, my toilet bag, take out my tablets and take them in their presence. The whole thing is just a joke now. (Participant 2)

Participant 9 exclaimed:

It's easier to take the treatment when she is around, I find it easy to take my treatment when she is around and I do not have to excuse myself, and go outside..., but when they are around. I have to find a way that I take them in a way that they are not going to notice. (Participant 9)

Participant 4 asserted:

I think...how can I put this...you take your treatment freely once you have disclosed, you do not really bother much because in my case I take them freely in the presence of my sister and boyfriend only because I have disclosed to them...but if you have not disclosed, you personally keep on asking yourself: what are these people going to say? What if they ask what these tablets are for? And they rattle a lot so you would end up lying, I lie to them. I really lie to people and tell them they are for asthma. What happens is that when people I have not disclosed to happen to be around., I take them out of the wardrobe, that is where I keep them...I hold them in my hand then get some water from the kitchen. They would ask me what the tablets are for and I would respond: They are for my asthma. (Participant 4)

The ARV-policy, assumed that disclosing one's HIV/AIDS status would be easier now that there is effective treatment, and that this would in turn make it easier to recruit treatment assistance, particularly among those who lived with the infected individual. The results of this study show that two types of disclosure have emerged viz. internal and external disclosure. 'Internal disclosure' happened when participants disclosed to their immediate family member (i.e. sibling) and when that immediate family member was willing to act as a treatment assistant. 'External disclosure' in contrast, happened when participants admitted to a friend or fellow support group member, that they were HIV-positive. In both cases of 'Internal and External' disclosure, participants chose individuals they were not sharing homes with. That is, for both 'Internal and External disclosure,' treatment assistants were not living with the participants. A common reason given by the participants for the certain individuals they had chosen to be their treatment assistants was based on the support these assistants could offer them. They stated:

She is the kind of a person...I think she was a social worker. She is very empathetic to other people I went to her and told her: I will be starting with drugs, and the other thing is that you know I am a drinking person and these drugs ought not to be combined with alcohol, so please I want you to keep an eye on me and encourage me to stop the alcohol and continue with my treatment. (Participant 2)

Participant 4 mentioned:

The reason why I told him is because he always reminds me whenever I am on treatment. I knew he would remind me to take my ARV treatment. I knew he would be capable of saying: 'Lungi, it is nine o'clock now, take your treatment.' (Participant 5)

A similar account was given by Participant 10:

My sister is my treatment buddy and she reminds me to take my treatment. She is a kind person and she is one person that used to help me a lot the time I was sick. I wanted her to keep an eye on me in case something happens to me. (Participant 10)

Participant 9's reason for disclosing to her friend was the following:

I decided to disclose to her because I wanted her to keep an eye on me, since I was told that the treatment had side-effects. (Participant 9)

Participant 6 asserted:

I disclosed to my cousin because I wanted her to remind me take them. I did not want to forget taking them. (Participant 6)

As illustrated by these quotations, participants chose to confide in specific individuals because they knew that they could rely on them for support. The support included reminding the participants to take their medication at the correct time, or keeping an eye on the participants while these were receiving treatment, and taking them to health officials if there were side-effects. Such treatment buddies, as they are sometimes called, can also help participants to feel that their HIV/AIDS status is accepted, and that they are not abandoned. The fact that the participants shared this information with these particular individuals also meant they trusted them and felt

safe enough to share this information with them. In return, they hoped that their treatment assistants would be empathetic to them, which would help them to adhere to their treatment schedule as well as to provide them with a safety net in the form of someone who would take them to the doctor in case they needed medical attention.

The results show that, although participants were open with their treatment assistants, they nonetheless to some extent preferred their treatment assistants to assist them discreetly. Participant 2 explained:

Mam'Tshaba used to be my treatment assistant. So what would happen is that Mam'Tshaba would come...Mam'Tshaba would be at my home at eight o'clock that is when I took my ARV treatment. I did inform her about my situation, that is, I had not disclosed to him. So Mam'Tshaba agreed to come at eight o'clock, so Mam'Tshaba would come and that is when I would take my ARV treatment. (Participant 2)

Discreteness for Participant 8 on the other hand, was upheld through by her treatment assistant reminding her to take her treatment in the form of sending her text messages whenever it was time to do so:

It happens all the time. What she (i.e. treatment assistant) does...actually, what I said to her was...she would send me a call back at 9 and in it, it would say "please call yitya" (i.e. please take your treatment) so every time I receive a call back from her, that would be my cue to take my treatment. (Participant 8)

Participant 10 stated:

She takes her treatment at 9 and she is my main neighbour. So what happened was that she would call me at 9 o'clock: "Fezi" and that would be a hint that it was time for me to take my tablets. I would also call her: "Xoli" those are the kinds of favours we do for each other. (Participant 9)

Participants' cautiousness concerning the taking of their medication and keeping this secret or confidential, is further proof of their fear that their HIV/AIDS - status could be revealed to the members of their household. Participants were thus aware that being accepted by their treatment assistants did not necessarily mean that other individuals would also accept their HIV/AIDS status. To prevent the potential

negative consequences resulting from disclosure to others, treatment assistance took place in various discreet ways.

The results further show that the ability to access treatment played a role in whether participants disclosed their HIV status to their treatment assistants. This was expressed in the following manner by the participants:

If there weren't any ARV's I would not have told her. I told her... I told her because I was told to bring someone along and I was also eager for my health to improve. (Participant9)

Similar views were shared by Participant 2:

Hey! I do not think I would have disclosed, because... I would not have disclosed, there would not have been any benefit for disclosing. (Participant 2)

From these statements it is evident that the availability of effective treatment has to some extent played a role in participants disclosing their HIV status. However, it can also be deduced from their remarks that participants did not necessarily find the task of disclosing easier now that there was effective treatment available. They mainly did so because it was a prerequisite for accessing the treatment. In other words, if they had not disclosed their status to someone, they would not have been given the medication. Although the results reveal that participants were initially sceptical of disclosing their HIV/AIDS - status before starting with ARV treatment, the trend suggests that participants found it easier or more bearable to disclose their status after being on treatment for some time. In other words accessing treatment did not just stand as a main disclosure catalyst. It appears that, after participants had taken the medication for a while and after its efficacy had been 'proven' to some extent, then talking about their HIV/AIDS -infected status extended beyond just sharing this information with their treatment assistants, but extended to sharing with close friends. The following are some of the participants' views on how ARV treatment has affected their disclosure after treatment proven effective:

The reason why I am disclosing is pride, pride. The pride that I can access effective treatment. That is the reason why I told my friend (Participant 2)

Similarly, Participant 3 stated:

The treatment has had a major impact on me talking about my status, because after I began with the ARV's, I started feeling alright, because I hardly get sick. For this reason, I thought I should tell Thandi about my status. (Participant 3)

Furthermore, Participant 4 asserted:

These ARV's have played a big role in my disclosing about my status. I was thinking about how effective they were so I thought I could tell some of my best friends about them. To tell those who have not started taking them not to be afraid to do so, they are very useful especially if you follow their instructions. (Participant 4)

Participant 10 is the only participant who expressed the feeling that the treatment has not encouraged her to disclose, even though the treatment was effective. She explained:

My having access to treatment does not have any impact on me disclosing about my status, because I do not want to lie.... I do not disclose about my status, I do not disclose, disclosing is not easy. (Participant 10)

Participants' views suggest that they were content with regard to the effectiveness of ARV-treatment and that they felt that the treatment had encouraged them to disclose their HIV/AIDS status. The ability of participants to access treatment and the positive effects this has had, most likely helped them to regard themselves as 'whole or complete' again, and to overcome feelings of helplessness after learning that they were HIV-positive. To some extent, it allowed them to 'reclaim' the world they had lost after being diagnosed with HIV/AIDS. However, the accessibility and effectiveness of treatment did not always lead to participants finding it easy to talk about their status. For instance, Participant 10 said that the dread of disclosing her HIV/AIDS-status persisted, despite her having access to the effective treatment. Remaining silent about one's status may protect individuals against possible negative effects, but at the same time it hampers their ability to follow the treatment schedule.

4.2.5) SIGNIFICANCE OF SUPPORT GROUPS

The following section describes something different, the significance of support groups in the life of HIV positive women. In addition, the results highlight participants' level of contentment as members of support groups, as these allow them to feel more at ease when talking about their HIV/AIDS status. Participants stated:

Being involved in Selina's support group has been something positive in my life, because we share and talk about issues. (Participant 8)

Participant 9 stated:

I feel very free when I attend my support group, because sometimes you would have a problem. We would share about our problems and it is through sharing that you start realising: Why am I stressing myself about this problem, this person's problem is even worse than mine and she is doing okay. We learn from each other so when I attend my support group I feel well, because we get to talk about anything and everything with these people, because we are all sick, so I feel free when I attend a support group. (Participant 9)

Participant 6 asserted:

I am happy. I am so happy for being part of a support group, you would not believe. I just love being part of it. When they greet me they say: Molo mama wase Luvuyo (Good day mother of Luvuyo i.e. the name of the organisation) and I say: Molweni bant'bam (i.e. Good day my children) others want to know where Luvuyo is, but I always tell them, you will never know women's stories, leave it at that. (Participant 6)

Participant 4 mentioned:

I enjoy myself a lot there, because the people there are very much like me. For instance, if one has a problem... perhaps one of the support group members once had a problem similar to yours, you would then get advice from people. (Participant 4)

Allen (2003) suggested that support groups are powerful forces, which provide valuable psychosocial support to individuals for the various challenges they face.

Participants unanimously agreed that they enjoyed attending support groups and benefited tremendously from them. The reasons for their contentment was that participants felt that they were in a safe and accepting environment amongst individuals who shared the same HIV status as them and who assisted them in 'learning to survive' with an HIV-infected status. 'Learning to survive' meant sharing-through talking about their challenges (i.e. social and health-related challenges) as well as through accessing a variety of advice from fellow support group members.

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CHAPTER 5

DISCUSSION OF RESEARCH FINDINGS

5.1.1) Fear of exacerbating the illness of already ailing elderly parent:

The findings indicated that some of the participants were fearful of disclosing their HIV-status to their mothers because they believed that such news would worsen their already ailing mothers' medical condition. Although these participants had cited this as their reason for not disclosing to their mothers, which may indeed have been true, there however appeared to be more to this reason. It may have been that participants were actually more afraid of being stigmatised by their families than abstaining from disclosure because they believed that it would be detrimental to their mother's health condition. For instance, seeing that HIV/AIDS is a virus that targets the immune system, thus manifesting itself through opportunistic illnesses and progressively observable symptoms, these participants were already receiving treatment, which means that their symptoms may already have been evident. or if they were not, they would eventually become evident to participants' mothers or at least they might have suspected that all was not well with their daughters' health, given the visibility of the associated symptoms when the disease progresses. Nonetheless, participants seemed to be afraid to admit to their mothers that they were HIV-positive. most likely because the negative experiences of others once they disclose an HIV/AIDS-infected status to their families had taught them that they too might be rejected by their own families.

Also, the voluntary nature of contraction, in which HIV tends to be posed in, may have played a role in participants' fear to disclose to their mothers. Perhaps participants were afraid that their families would blame them for having contracted the virus, this is in addition to participants also blaming themselves for having contracted the virus. This blame may have led to participants experiencing feelings of shame at having been infected. It may have also given rise to a sense of having somehow failed their families. This is because HIV-infection tends to not only have a negative social effect on the infected individual solely, but also tends to be viewed as reflecting negatively on that person's family and background. It is thus likely that participants felt that they had 'misbehaved' in some way by contracting the virus and that they did not want to embarrass their families or tarnish the family name. It could

thus be deduced that participants' failure to disclose their status in this instance, appeared to stem from a desire to protect both themselves from the possibility of being discriminated against both within and outside their households (should the news about their status spread), as well as to protect their families against the possible shame that the public knowledge of their status could cause in their neighbourhoods.

5.1.2) Fear of being accused of promiscuity:

In addition, results highlighted that the fear that they might be accused of having been sexually promiscuous, served as another reason why participants tended to remain silent about their HIV status both in their socio-cultural and religious contexts. The socio-cultural campaigns (i.e. the ABC campaign and virginity testing) aimed to combat the spread of HIV/AIDS-transmission by strongly emphasizing the voluntary and sexual nature of HIV/AIDS-transmission, may have played a role in participants' silence about their HIV-status as they may have been afraid that they would be blamed for having contracted the virus because avoiding transmission is considered to be entirely the responsibility of the individual.

Although transmission in South Africa happens predominantly through unprotected sexual intercourse, the fact that campaigns suggest that transmission is both voluntary and sexual in nature ignores other factors that play a role in HIV/AIDS transmission, which may not necessarily be voluntary. For instance, rape tends to be rife in poverty-stricken areas such as the ones where the participants of this study live, and this clearly is another mode of HIV transmission (especially if post-exposure prophylaxis treatment is not taken). Obviously, such sexual intercourse is not voluntary and could play a role in the transmission of the virus. As was already mentioned, the campaigns overlook the inherent power dynamics that tend to exist within heterosexual relationships. These include, for instance, the gendered roles involved in sexual conduct, such as the fact that it is socially acceptable for men to have multiple partners as well as a sign of masculinity to not use a condom during sexual intercourse. Conversely, it is socially required for women to be monogamous; accepting and obedient to male sexual requests even when the male partner refuses to use a condom. As a result of such gender-based roles, women are easily exposed to HIV-infection.

An additional reason that could have exacerbated participants' fear of disclosing that they were infected with HIV/AIDS is because they come from socio-cultural backgrounds, where females are regarded as 'flowers,' signifying 'purity' and 'innocence', specifically in a sexual way. Consequently, women who are virgins and not yet married or women who are monogamous (i.e. married) are associated with 'purity', 'innocence' and 'goodness'. Given the sexual nature of HIV transmission, then, women who are infected with HIV/AIDS are considered as indirectly revealing their sexual behaviour. Some of the participants may have thus been afraid to disclose their HIV-status as they risked being viewed as sexually promiscuous or sexually indulgent, sexually 'immoral' or 'bad', which means that they would no longer be associated with the traits of 'good females' (i.e. innocence and purity).

Religion, with its emphasis on the 'purity' of women may have played an additional role in women's fear of disclosing their HIV-status in a religious context or to their church-going friends. For instance, participants who were never married were afraid that being HIV-positive would be an obvious indicator that they were 'sinners', i.e. that they were indulging in sexual activity outside the state of matrimony, which is frowned upon by the church, as individuals are supposedly expected to remain 'pure', i.e. to maintain their virgin status until they marry. These participants may have been afraid that they may be accused of having had or having multiple sexual partners. The interconnection of these factors (i.e. of being sexually active out of matrimony and of being perceived to have multiple sexual partners) could have made church-going participants afraid that they would be accorded less value at church, and even that they would be stigmatised or ostracised by their fellow church-members.

It should be borne in mind that some of the participants had leading roles in their respective church, and that such a revelation could taint their reputation amongst the members of their congregation. For instance, some of the participants went to churches that are strict in terms of dress code and social conduct, more especially if one occupies a leadership role in church. For example, in such churches, a woman in a leading position who falls pregnant out of wedlock, is likely to be cut off or demoted from her position of leadership. One can only imagine the possible sanctions that could be put on an unmarried female with an incurable, sexually-related condition

such as HIV/AIDS. Such leadership roles are valued by those who hold them because they heighten their standing in the church and in the community, thus being demoted from them is considered a shame or an embarrassment. Some of the participants may have been afraid to disclose their status to their church-going friends because if such news would spread, it would have negative implications on the leading roles they held at church. It would create the impression that they were not only sexually promiscuous, but that they are 'diseased' and 'dirty' and that they have been conducting themselves sinfully by engaging in sexual intercourse out of marriage. Remaining silent about their HIV-status could have thus been participant's attempt to avoid such negative labels especially from such a place of righteousness. For some of the participants, church is where they draw hope and resilience from, with regard to living with HIV/AIDS. Thus, to avoid the 'embarrassment' of one's sexual activeness being made public and to avoid being excluded from a system in which one holds a good reputation, participants may have preferred to remain silent as it was their only solution of avoiding such negative consequences associated with disclosing an HIV/AIDS-infected status.

5.1.3) Fear of being rejected by the partner:

Findings further highlighted that participants were afraid to disclose their HIV-status to their partners because they were afraid that their partners would reject them, which would have serious socio-cultural and economic repercussions. A first reason that could be suggested for this is that since the participants come from a cultural background that encourages heterosexual relationships and values women who remain in a marriage relationship or with their partners irrespective of the conditions of such relationship, rejection by the male partner would be viewed as a social shame in their neighbourhoods. The value placed on marital relationships in participants' cultural backgrounds is expressed through adages such as '*Indoda iyanyanyezelwa*' (i.e. a man ought to be tolerated). Such adages put so much value on partnership that women tend to remain in relationships even if they are unpleasant or abusive, as marriage or partnership is seen as the essence of 'womanhood' and thus accords women social respect. Women who are rejected by their partners are culturally seen as failures who lack the essence of womanhood and are thus accorded less respect and value than those who remain in relationships regardless of the circumstances.

As a result of the stigmatising nature of HIV/AIDS, then, the participants may have been afraid that their partners might abandon them if they told them about their HIV status. Furthermore, if their aggrieved male partners decide to talk about it, or even to disclose the woman partner's HIV-status, participants may have feared that it would further jeopardise their standing in the community and increase their chances of being ostracised by their family members and the community at large. Given such negative circumstances, participants may have considered the silence about their HIV-status as the best option.

A second reason, which may have contributed to participants being silent about their status, is that some of the participants may have feared that their partners may become physically violent if they disclosed their HIV-status to them. More than half of the participants had reported past incidents of violence at the hands of their partners. Negative social stereotypes, which consider women to be natural carriers of the HIV-virus, as was put forward in Leclerc-Madlala's (1999) ethnographic study viz. the view, that women are a natural source of 'contamination', may play a role in justifying the violent reaction male partners react in when their female partners disclose their HIV-status to them. Not only may the participants have been afraid that they would be attacked by their partners, but they may have also feared that they could be blamed for having caused the violence because they are viewed as the source of contamination.

A third reason, which may have played a role in participants' lack of disclosure to their partners could be that their personal experience may have shown that family members may not necessarily be supportive in a manner that discourages the recurrence of the violence, family members may not want to 'interfere', instead they would encourage them to 'talk things through' with their partners, as violence is considered a masculine trait. In addition, their experiences have shown that police officials may not attend efficiently to cases of domestic violence – leading to the violence persisting. In view of the above reasons, participants may have been afraid that they would feel helpless in such circumstances, where their male partners not only become physically violent towards them, but where the female partner is in fact blamed for the violence and, even worse, does not receive support from families or

the police. As a result, participants may seek to protect themselves by refraining from disclosing their HIV-status to their partner.

5.1.4) Fear of losing economic support:

In addition to the above fear of being rejected or attacked by their male partner if they admitted that they were HIV-positive, participants were also worried about the financial challenges they would face if their partners were to abandon them. As the participants in this study were not formally employed, their main income was either through a child's grant or through an HIV/AIDS-disability grant. However, as the participants usually come from poor families and contributed to the upkeep of the family with their grant money, they usually could not cover all their costs and as a result had to depend on their partners for additional financial assistance. Participants' dependence on their partners for financial assistance was further aggravated by the inconsistency of their eligibility to access the HIV/AIDS disability grant.

The Department of Social Services and Poverty Alleviation (2002) specified that unemployed individuals with full-blown AIDS (i.e. with a CD4 count of less than 200 i.e. the stage at which infected individuals are deemed eligible to start with ARV treatment) are to have access to an HIV/AIDS disability grant, as their state of health during such a stage of the disease means that they are often unable to work or remain in formal employment. The aim of the grant is thus to assist them financially in order for them to maintain a healthy diet, given that proper nutrition is vital when one is taking ARV-medication. The downside to the disability grant, however, is that as soon as there is an improvement to one's health (as shown by the increase in the CD4 count), the grant is withdrawn, because individuals are now considered healthy enough to either go back to work or to seek employment.

Although the Department of Social Services maintains that, by withdrawing the disability grant, it is curbing the syndrome of 'handing out money without working,' this actually has negative implications on infected individuals' health, because, if they were unemployed before they were diagnosed with HIV/AIDS, they will not necessarily become employed just because the treatment has improved their CD4 count. In fact, just because their health has improved somewhat due to treatment,

there is no guarantee that they will obtain employment, which seems to be the rationale behind the grant. Thus, the granting and withdrawal of the grant can potentially create a cycle of sickness and health. When unemployed individuals have access to the grant (which in most cases could be their sole source of income), they are presented with the opportunity to access nutritional food which would work in conjunction with ARV-medication to improve their health. However, once the grant is withdrawn and if they remain unemployed, they will no longer be able to afford the nutritional food, and are thus more likely to experience stress, which would have a negative impact on their already compromised immune system, raising the chances of them becoming sick again. Clearly, this cycle undermines the effectiveness of the treatment. Additionally, it is also possible that individuals living with HIV may deliberately not adhere to their ARV-medication with the attempt of maintaining a steady low CD4 count as a means of securing the disability grant. The dire implication of this is that it increases the infected individual's chances of becoming resistant to the ARV-medication.

Given the above, it is understandable that those participants who were receiving the HIV/AIDS disability grant and were experiencing the nutritional benefits of proper nutrition, may have been fearful of disclosing their HIV-status to their partners. As the HIV/AIDS disability grant was likely to be withdrawn at some stage, it is likely that participants may have been trying to ensure that there would be someone who would financially support them when they could no longer qualify for the grant. This may not be possible if they disclosed their HIV-status and if their partners rejected them. Additionally, the participants may also have been reluctant to disclose their status because they wanted to ensure that their children would receive schooling and be able to provide for themselves after they had passed on. By contributing to their children's education, participants may have been trying to prevent their children from experiencing similar financial challenges to the ones they were currently facing. Maintaining secrecy about their status from their partners could have thus been participants' manner of ensuring regular financial assistance from their partners, which would assist their children receive an education in order for them to be able to take care of themselves in the future.

Apart from anticipating a loss of economic support, participants may have also been afraid of being rejected by both their partners and their families, as they would thus be alone and not have anyone to support them during this difficult period. By observing how other HIV/AIDS-infected individuals have been negatively treated by their family members after disclosing their HIV-status, participants may have been afraid that they might be treated in a similar way. Participants may have been afraid that if their family members chased them away, they would lose moral support and economic assistance (if the HIV/AIDS grant was withdrawn too). By remaining silent about their status, participants were trying to remain in their respective families and to make sure that at least some of their basic needs were met if they were unemployed and no longer receiving the disability grant.

5.1.5) Disguising an HIV-positive status:

Given the challenges discussed above, participants were afraid to disclose that they were HIV-positive: because they were afraid that they risked being rejected and abandoned by both their partners and their family members; they risked being accused of having been sexually promiscuous; as well the risk of losing economic support. As a result, they pretended to suffer from socially less stigmatised illnesses so as to ensure that they decreased their chances of being discriminated against. Through pretending to be suffering from illnesses such as arthritis; T.B. and sugar diabetes, participants may have believed that these were among the only ailments that would ensure that their families would not reject them, unlike the case would be if they disclosed an HIV/AIDS-infected status.

The fact that these illnesses are not sexually transmitted, thus accorded less stigma, may have played a role in participants preference to pretend to be suffering from them, instead of HIV/AIDS. For instance, although sugar diabetes, like HIV/AIDS is incurable and could potentially be deadly and chronic if medication is not adhered to, participants would rather pretend to be ailing from it instead of HIV/AIDS. Given the sexual nature of transmission of the HI-virus, participants may have believed that their family members would blame and accuse them for having been sexually promiscuous and irresponsible because, after all, family members could be under the impression that through condom use they could have prevented viral transmission.

Due to such negative association attached to being HIV/AIDS-infected, it is possible that participants may have believed that they would be less stigmatised if they pretended to have a different illness. Instead, they would be able to maintain the manner in which they related with their family, as well as receive more support from them (because of their health condition), than the case would be if they disclosed an HIV/AIDS-infected status.

In addition, results have shown that pretending to suffer from other illnesses made it easier for some of the participants to adhere to their schedule of ARV-medication, because family members were under the impression that it was for the less stigmatised illnesses participants pretended to be suffering from. Seeing that participants were not ostracised by their families when they presented less stigmatised illnesses to them, they may have experienced feelings of acceptance, which are amongst the crucial feelings when one is being diagnosed with an illness such as HIV/AIDS, which had the potential of one being rejected by the people s/he has been relying on all her/his life. Seeing that pretending to suffer from other illnesses than disclosing an HIV-status, seemed to be more accepted by their families, it may have reinforced participants' decision to keep their HIV-status a secret from them. The reason being that it made participants feel secure, seeing that they were already experiencing feelings of guilt and fear, they may have believed that there was a potential of such feeling intensifying if they disclosed to their family members and if they became judgemental in turn. Participants may have thus believed that pretending to suffer from other illnesses was the only manner through which they could ensure that they protected themselves from the possibility of experiencing such adverse effects (i.e. being judged or abandonment by their family members) associated with disclosing an HIV-infected status.

5.1.6) ARV-treatment taking strategies:

The results indicated two types of treatment-taking strategies participants employed when they had to take their medication. Although the majority of the participants had not disclosed their HIV-status nor told the truth behind taking ARV-medication to their family members, one group of participants always aimed to ensure that family members were out of sight when they had to administer their medication, whereas the

other group went ahead and took their medication in the presence of their family members. Due to the negative consequences that could arise if their family members were to find out about the real reason behind taking medication, the first group may have considered taking medication in the absence of their family members as having been ideal. The reason being that it saved them from the possibility of accidentally admitting an HIV-positive status, due to the constant questions that they would be exposed to every time they are seen taking medication.

On the other hand, seeing that the presence of family members did not have an impact on their treatment taking, in contrast to the other group, the second group of participants did not have to engage in strategies that would ensure that their family members were out of sight. Instead they may have considered it plausible to take medication in the presence of their family members, because they could always justify this to the illness they had pretended to be suffering from. Unlike the ARV-policy's view which maintained that it was easier for individuals to adhere to ARV-medication when they have disclosed compared to when they have not, it emerged from the results, that there was a correlation between non-disclosure to family members taking medication in secret and medication non-adherence; as well as a correlation between non-disclosure to family members; taking treatment in the presence of loved ones and treatment adherence. This could be explained as follows: seeing that the first group of participants did not disclose an HIV/AIDS-infected status to their family members, they could not openly take their medication, instead they had to engage in strategies (such as ensuring that family members were not in sight when they took their medication so as to avoid interrogations concerning taking treatment) which were not always possible to maintain, leading thus to participants not always taking their ARV-medication on time.

Although the second group of participants just like the first one, had also pretended to be suffering from other illnesses instead of HIV/AIDS, the second group of participants were however able to adhere to their medication, because they could attribute taking it openly to the various illnesses they had deceived their family members to be suffering from, leading them to adhering to their specific treatment-taking schedule. However, in contrast to the ARV-access policy, which offered the implication that adherence was mainly possible if one disclosed to her/his family

members, the results from this study highlighted that although lack of disclosure could pose a challenge in terms of adhering to ARV-medication, such was not necessarily conclusive, as results have shown that it was possible for individuals who did not necessarily disclose their HIV-status to their family members to adhere to their ARV-medication.

The results further highlighted that participants employed additional strategies to conceal their status. This was achieved by: a) participants collecting their medication from collection sites that were outside their areas of residence even if provision was made within their neighbourhoods, as well as b) deceiving significant others about the purpose of support groups. Such results demonstrate that although participants may have been successful in hiding their HIV-status, as well as the reason behind taking ARV-medication to their families, participants feared their HIV-status being known by their families and people in their neighbourhood, as a result they considered collecting medication further away from their neighbourhood as the safest option to ensuring that their status was kept a secret from families and neighbourhoods. This is due to the stigmatising nature in which medication is collected at collection sites (i.e. site located outside the clinic and set aside specifically for ARV-medication or different points of treatment collection for ARV-medication within the same clinic). Participants may have been afraid that there was a great chance of them being recognised if they collected their medication from sites within their neighbourhoods, because being spotted at such collection sites by familiar people, would be a give away of their status or at least it would lead to the familiar people having suspicions about their HIV-status.

Participants may have been afraid that these familiar people would divulge this information until it reaches their families, from whom, participants were keeping this information from. Participants may have been afraid that their family members may not take the news well and could thus lead to them being discriminated against within their household. Such findings illustrate that unlike the ARV-access as well as other theorists (Siegel, Lekas & Scrimshaw, 2005); Stein (2005) have maintained that disclosing an HIV-status would be an easy task now that there is effective treatment that has the potential of altering the virus from being viewed as incurable and deadly disease to chronic, but manageable. Results instead showed that irrespective of the

effective medication, HIV/AIDS still continues being a stigmatised disease leading to participants going through the inconvenience of taking their medication in secret and collecting it out of their areas of residence, despite ARV-medication provision being offered within their own neighbourhoods. For instance, although participants continued collecting treatment and it improving their health condition, due to the stigma attached to HIV/AIDS, participants who may have feared disclosing their HIV-status to their family members, because personal experience or observation made participants realize that the disclosure of an HIV/AIDS-infected status may not be well-received by family members despite there being effective medication available. Thus as an attempt to prevent rejection or other adverse consequences from happening, in addition to pretending to suffer from various illnesses, as well as not telling the truth about the real reason behind taking ARV-medication, participants may have considered their treatment collection sites outside their neighbourhood as having been their additional manner of attempting to ensure that their status was kept a secret from their family members.

As an additional strategy of being discreet about an HIV-status, participants concealed the real reason behind their attendance of support groups, where they got food from. Concealing their attendance of support groups entailed participants intentionally not mentioning the concept 'support group' and attributed the food they got from support groups to women committees, aimed at providing economic assistance to unemployed women. Seeing that the HIV/AIDS epidemic has led to the vast emergence of support groups, participants may have believed that the mention of the concept (i.e. support group) would indirectly give away their HIV-status, because the concept or attendance of such forums has come to be synonymous with being HIV/AIDS-infected. Thus, participants may have believed that mentioning that one was attending a support group was synonymous to telling others that they were HIV-positive as a result they may have considered pretending to be accessing the food from committees instead of support groups, was the only manner through which they could keep the information about their HIV-status a secret.

5.1.7) Disclosure and patterns followed when taking treatment:

The ARV-policy assumed that it would be easier for HIV/AIDS-infected individuals to disclose their status to their family members in order for them to operate as their treatment assistants, seeing that there is effective ARV-medication available. However, the results of this study have shown two types of disclosure i.e. internal disclosure (to immediate family members) and external disclosure (to a friend or fellow support group member). From participants' choice of treatment assistant, it could be deduced that participants were so afraid to disclose to family members that they lived with, instead they found the task of disclosing to friends, support group members or immediate family members (e.g. a sister whom they did not live with) much easier, especially if the treatment assistant was not living with them. Participants explained that they would prefer to get support from treatment assistants outside the home (i.e. being reminded to take treatment, keeping an eye on them while they were on treatment and being presented to health officials in the case of side-effects). Although these reasons are plausible, there seemed to be more to participants' choice of treatment assistants than the reasons the participants offered. For instance, although the kind of support, which participants maintained led them to disclose to their outside treatment assistants given the chance could have been accessed or offered within their household. This leads one to suspect that the reason for participants to choose outside treatment assistants was possibly because they were afraid that they could be discriminated against or stigmatised if they did so within their households. For instance, it may have possibly been easier for participants to receive the kind of assistance (i.e. being reminded to take treatment, keeping an eye on them while they were on treatment and being presented to health officials in the case of side-effects) they were hoping to obtain from treatment assistants, if assistants were living with them compared to when they were not. Nonetheless participants preferred sharing the news of their HIV-status with treatment assistants who were living outside their homes than the ones they shared homes with. Seeing that participants may have possibly been afraid of being stigmatised, hence their choice to disclose 'externally,' could have been inspired by participants believing that even if their chosen treatment assistants were to treat them badly or possibly stigmatise them, at least it would be outside the home-in the home itself, such treatment would be more intensive and more stressful and thus more detrimental to their health.

To further ensure that they do not arouse the suspicions of their family members, participants made it clear that treatment assistance should be given discreetly (i.e. by discreet reminders to the infected individual to take their medication at the scheduled times). Participant's discreetness about taking their ARV-medication acted as proof that they did not want their family members to be aware of their HIV-status. For instance, even for the participants who considered taking medication in the presence of their family members easy (seeing that they externally disclosed), there may have been an underlying fear of 'what if' their family members knew or through the media discovered what the tablets looked like, as this could lead to the discovery of their status. However, seeing that they wanted to keep this information hidden, they had to act as if 'all was normal' i.e. they were adhering to the medication that they pretended to ail from.

Results additionally highlighted that both groups of participants (i.e. those who have internally and externally disclosed) took their medication easily and openly in the presence of their treatment assistants. The reason for this kind of treatment administration is that participants may have felt that their treatment assistants were aware and accepting of their HIV-status, thus they did not need to engage in the various strategies they employed (particularly those participants who required absolute privacy when they took their medication) when they took medication in the presence of individuals to whom they had not disclosed their HIV-status to.

Results furthermore showed that taking ARV-medication together with being involved in a support group have to some extent both played a role in participants' disclosing beyond their treatment assistants. Participants mentioned that after having been on treatment and through attending support groups, they found the task of disclosing to other individuals who were not necessarily their treatment assistants easier. Participants however continued keeping this information a secret to the family members they shared their mothers with. It could be deduced from these results that the fact that taking ARV-medication together with attending support groups was proving helpful in terms of the medication improving one's health condition and support groups offering a supporting and empathic environment, thus increasing the chances of accepting an HIV/AIDS-infected status. Participants may have considered

the 'burden' of being HIV/AIDS 'lighter', as both the medication and support groups were steadily helping them overcome the negative feelings associated with an HIV/AIDS diagnosis.

The fact that participants only seemed comfortable sharing the news of their HIV-status with close friends and family members they were not living with, instead of family members they shared their homes with, could have been due to the fact that participants may have believed that, although the medication may have been successful in improving their health condition, they still had the virus, and for this reason it would not stop their family members from stigmatising them. Due to this fear, participants may have considered it essential to keep their HIV-status a secret.

Due to the stigma attached to an HIV/AIDS-infected status, participants had to adopt various strategies to take their treatment. For instance, participants tended to either take their medication only when their family members were in a different room in the house or they completely vacated the house every time they had to take their medication. On the other hand, participants used the excuse of pretending to suffer from other illnesses, as license to take their medication in the presence of their family or household members. From this tactic, it could be argued that participants may have been an underlying fear of 'what if' their loved ones knew or through the media discovered what the tablets looked like, as this might lead to the discovery of their HIV-status. Despite these anxieties, the results illustrate that there was a correlation between taking treatment in the presence of family members and treatment adherence, as well as a correlation between taking treatment in secret and treatment non-adherence. The first group was able to take their medication openly because they have misinformed their family members about the real reason behind them taking medication. On the other hand, although the second group had also misinformed their family members about the real reason behind taking medication, because they required privacy when they had to take medication, they were not always able to take their medication at the specified times, because their family members sometimes occupied the rooms in which they kept their treatment. Participants may have thus been afraid that being seen by their family members while they took their treatment, may have led to them being interrogated about such treatment and may lead to them confessing that they were HIV-infected.

The results further showed that participants employed further strategies to conceal their status. For example, the participants usually collected their ARV-medication from collection sites outside their own areas of residence, even if there were collection sites in their neighbourhoods. The reason they gave for this was that due to the stigmatising set up of ARV collection sites (i.e. either the ARV-medication collection site being located outside the clinic or the point of medication within the same clinic differing) it increased the chances of others finding out about their HIV-status. As an attempt to keep this information a secret, participants opted to collect their medication outside their areas of residence though provision was made within their areas of residence. As an additional manner of concealing their HIV-status, participants tended to deceive their significant others about the real purpose of attending support groups, as the concept 'support group' would 'reveal' or lead others to have suspicions about their HIV-status.

CHAPTER 6

STRENGTHS AND LIMITATIONS OF RESEARCH

Previously conducted studies have mostly focused on women's experiences of living with an HIV-infected status; attitudes towards individuals living with HIV/AIDS-infected status; prevention programmes as well as drug trials. This study is one of the first studies to offer insight towards some of the women's lived realities about the psychological challenges associated with disclosing an HIV/AIDS-infected status and the impact such challenges have on adhering to ARV-treatment.

The in-depth, semi-structured nature of interviews conducted in *IsiXhosa*, allowed participants to give detailed knowledge about the topic in a language they felt comfortable expressing themselves in.

However, although conducting the interviews in the participants' home language has been beneficial, having to translate the interviews from *IsiXhosa* to English is problematic, because the themes that come up spoken by participants in *IsiXhosa* do not necessarily convey what is being said when they are translated in English.

The fact that I am a black, *Xhosa*-speaking female may have encouraged participants to feel comfortable in sharing their lived experiences with me. Alternatively, these same characteristics may have counted against my favour and led participants to be selective in what they shared about their lived experiences. For instance, although I am black and am a *Xhosa*-speaking female, I come from the middle class, am receiving a tertiary education and am younger than them, such factors may have led them to believe that I would be biased and not listen to their lived experiences empathetically.

The fact that one of the participants was the same age as myself could have been in or against my favour. For instance, the participant may have felt comfortable sharing her lived experiences with me because we are the same age and she would therefore assume that I would be an empathetic listener. Alternatively, she could have been selective in what she shared with me because although we are both black, *Xhosa* and female, power differences i.e. the fact that I come from a different class to her and

attend a tertiary institution could have led her to hold assumptions about my HIV status. Thus she could have felt shameful about herself for not being in a similar position - and she may have consequently restricted the information that she shared with me.

This study focused on women of differing ages; within a particular context and geographical group whose duration of treatment varies. The results of this study are therefore contextually bound and cannot be generalised to all women who are on ARV-treatment. For example, a similar study focusing on women who are middle-class, are part of a certain age group and who live in a rural context, could yield different results.

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CHAPTER 7

IMPLICATIONS AND RECOMMENDATIONS

From the interview transcripts it is possible to identify various opinions concerning the psychological challenges associated with disclosing an HIV-positive status and how such impact on adhering on ARV-treatment. Being aware of such opinions makes it possible for probable recommendations to be made concerning living with an HIV-infected status, ranging from challenges such as choosing and disclosing to treatment assistants in order to access treatment, as well as adhering to treatment once it is accessed.

7.1.1) Counselling Services:

Despite the availability and effectiveness of ARV-treatment, it was evident from participants' narratives that it is a lived reality that an HIV/AIDS-infected status remains stigmatized, thus the counselling service that gets offered before one's HIV/AIDS status get divulged, which potentially plays a role towards the individuals' gradual acceptance of her/his status, should it be positive, should acknowledge and address this fact sensitively. Firstly, judging from the participants' narratives, it seemed as if some improvements concerning the kind of counselling participants receive before they are told about an infected status could be beneficial. For instance, a unanimous procedure shared by the participants which seemed to have taken place during the counselling sessions before they got told about their HIV/AIDS-infected status was that HIV/AIDS counsellors asked them: "What would your reaction be if you were to find out that you are HIV positive?" and soon after that one's HIV-positive status would be revealed. This approach was blatantly condemned by participants, e.g. one participant stated: "The only time I received counselling was when I went for the HIV test, the only thing that nurse asked me was "What would you do if you were to find out that you are HIV positive?" That is not counselling!" Although it is a plausible idea for counsellors to enquire about individuals reactions once they discover that they are infected, as it allows for all sorts of possible reactions to be brought forth by the participants, and for "harmful" reactions such as committing suicide, could through communication and presenting possible options be prevented.

However, counsellors ought to receive specific training, which would enable them to be sensitive when they divulge this information. In other words, when divulging an HIV/AIDS-infected status in their counselling program, counsellors should take into consideration the possible psycho-social challenges that infected individuals would face with now that they are living with an HIV-infected status. For instance, as was evident from the study; when a woman discovers that she is HIV positive, not only does she have to deal with the negative emotions of such a discovery; she has to be concerned about how she is going to share such information with her loved ones; who she is going to choose to be her treatment assistant as required by the ARV-access policy; the possibility of being rejected by her family; the constant worry about her health and her children's well-being; and for those who financially depend on their partners there is a constant worry that their partners could be physically abusive or abandon them once they make them aware of this information. These are just some of the psycho-social issues that women become concerned about when they discover that they are HIV/AIDS-infected and it would be vital for counselling services to bear these in mind in order for services to be delivered sensitively and empathetically.

7.1.2) Attempts to de-stigmatise HIV/AIDS:

As it was already highlighted, the question of stigma, leading to discrimination and ostracism of HIV-positive individuals, needs to be addressed. The following are some suggestions for this: Leading/authority figures living with the virus could be invited in both social and religious contexts to talk about living positively with the virus to community members (both infected and non-infected). This kind of approach would show that the virus not only affects 'certain' individuals or poor individuals, but that it can potentially affect influential individuals as well. Another approach would be to encourage individuals who have been infected in various ways (i.e. through rape; within marriage from an unfaithful partner; by sharing of hypodermic needles and drugs; accidentally by being pricked with a needle; or through transfusions with infected blood) to talk about these various ways of contracting the virus. This would draw attention to the fact that the virus is not only transmitted through sexual 'immorality' or promiscuity. In addition, individuals who have been living with the virus for numerous years could also be invited to talk about their experiences and to highlight the fact that with effective ARV-medication, the virus can be changed into

manageable chronic illness, similar to sugar diabetes or high blood pressure, instead of being an automatic death sentence. Furthermore, from the results it was evident that misinformation or a lack of information about HIV/AIDS is contributing to society stigmatising individuals living with the virus. Thus it would be helpful to have volunteers present information sessions to teach communities about the facts of the virus (i.e. how it is transmitted and how it can be managed).

7.1.3) Support Groups:

It was evident from the findings that support groups were able to provide safe spaces, where the participants could share some of the challenges they were facing concerning living with the virus and where possible coping strategies could be proposed. Support groups are thus essential forums that provide therapeutic effects for individuals living with the HI-virus, more especially among women who cannot afford private therapy. The role that could be played by support groups in the face of the epidemic is that these forums should not only be spaces within which individuals only talk about their sad experiences, but they should also educate individuals about HIV/AIDS, ARV-medication and living with the virus itself. Also, seeing that violence from partners could be one of the consequences of disclosing an HIV/AIDS-infected status, should thus be active in linking with women with organisations, which deal with gender based violence. That is, women could receive advice in terms of handling the violence circumstances they are faced with.

The question of the disability grant being withdrawn also needs to be addressed. As was evident above, there are negative repercussions if the disability is withdrawn as soon as the infected individuals' state of health improves. The government could offer funding to support groups and encourage these to run their own programs and projects, which would enable infected women to make a living for themselves or at least to sustain themselves. By improving their economic status, the women would be offered an opportunity to access more nutritional food, which would enhance the positive effects of the ARV-medication and improve their state of health. Furthermore, by being able to sustain themselves, they might develop the courage to leave abusive relationships, given that it is usually a lack of financial independence that forces women to remain in such relationships.

7.1.4) ARV Access Policy:

As highlighted by the findings, it was difficult / challenging for participants to disclose their HIV-status to a family member (particularly the ones they lived with), as required by the ARV-policy as a prerequisite for accessing ARV-medication. As a result, participants sometimes presented acquaintances whom they were not living as family members in an attempt to access the medication. It emerged from the study that individuals are so eager to access the medication, but at the same time so afraid that their status could be divulged, that they sometimes presented acquaintances who live far away from them in an attempt to keep their status secret, because they may have been afraid that there may have been a chance that treatment assistants who reside within their areas of residence to be more likely to divulge the information. The danger of such far-away treatment assistants is that such treatment assistants may not necessarily have a close relationship with the individual receiving treatment and that they may not be able to monitor how the treatment is progressing. This has a negative impact on the treatment itself. The assistant may not be able to remind the individual consistently to take her medication, seeing that in such instances reminders are telephonical, treatment assistants may not necessarily always have the financial means to do so. In addition, the distance further makes it difficult for assistants to take infected individuals to health officials or clinics when they need to, because they may not necessarily be aware that the individual needs medical attention.

As an alternative to the policy requirement to access ARV-medication, the government should re-consider making it compulsory for individuals to disclose their HIV-status to a family member in order to access treatment. Instead, individuals should be offered the choice to disclose to whomever they wish as a prerequisite for accessing treatment. Before commencing treatment, then, individuals should be informed about the importance of having treatment assistants. If individuals are comfortable with disclosing their status to members of their households and if they believe that their family members would not be judgemental, they should then be allowed to do so, as this would count more in their favour, because they would not have to employ complicated strategies, which may not always be effective, to ensure that they take their medication on time, thus having reducing treatment adherence. If their household members, however, are supportive, then their chances of taking their

treatment freely and at the correct times would increase the chances of adherence and the effectiveness of their medication.

However, in cases where individuals suspect or fear that their family members would be judgemental if they were to admit that they are HIV-positive, then such individuals should not be forced to disclose to their family members. Instead, alternative options should be implemented to try and ensure that they adhere to the treatment regimen. Firstly, volunteers who preferably live close-by to the individuals could play a role. These volunteers who would act as treatment assistants should first be educated about ARV-medication and the importance of adhering to it, in an attempt to ensure that they take this role seriously. Given the stigmatising manner in which ARV-medication is provided by the ARV-collection sites (i.e. there are separate venues to collect medication), it would be ideal if treatment assistants could collect the medication for the individuals on the specific dates and in collaboration work out how treatment could be administered, i.e. whether it is best for treatment assistants to go to the individual's home to administer the medication or vice versa. This active involvement of a treatment assistant in administering the ARV-medication encourages a rapport between the individual and her treatment assistant, as the individual could share with her treatment assistant the medical challenges she is experiencing with the treatment. Volunteers could also present them to health officials when they become ill, while ensuring that the individuals are adhering to the treatment regimen. As a token of gratitude and reinforcement, treatment assistants could be offered certificates to acknowledge the crucial role they are playing in the face of the HIV/AIDS epidemic.

Secondly, if there are no volunteers willing to act as treatment assistants, support group members could act as each other's treatment assistants. For example, if one support group member's HIV status is known and accepted by her family, and if s/he lives near individuals who have not disclosed to their family members, support group members could organise to take the treatment at the same time at that particular fellow support group member's home.

Alternatively, the venue or home where the support group meetings take place could be used as a venue where the ARV-medication is regularly taken. This venue could

have lockers, in which the individual's ARV-medication is kept, and individuals could go there to take their treatment at the correct times. This kind of strategy could work optimally if the home where they take treatment is nearby or within walking distance of their homes. It is important that participants can easily walk to take their place of treatment, without being deterred by problems such as bad weather or lack of transport money. Also, taking treatment in this manner or in a group form could encourage adherence, as it forms a bond or connection between group members. It encourages a 'we are in this together' mentality. If a member were to miss the treatment, then fellow group members could follow up. Furthermore, another advantage of taking treatment collectively is that it allows individuals to talk about the side effects they are experiencing, to come up with possible suggestions of how to deal with similar treatment challenges, or alternatively to present each other to health officials when necessary.

The above are just some of the possible strategies that could be adopted as an alternative to the ARV-access policy in order to improve adherence to the treatment regimen. They are not necessarily foolproof because there is always a chance that these strategies may not necessarily work optimally i.e. it may not always be possible to keep individuals' taking of ARV-medication a secret, as maintaining secrecy about taking ARV-medication is not always possible when people are living in such close proximity to each other. But they may nonetheless increase the chances of accessing and adhering to the available treatment, as well as of being presented to health officials in the case of ARV-related challenges, as it was initially intended by the ARV-access policy, without having to disclose one's status to one's family members. Thus, it may not be necessary to deceive health officials by presenting friends or acquaintances as family members in order to access treatment. Such friends may not necessarily feel obligated to monitor treatment adherence and effectiveness. When volunteers are used to be specifically responsible for this task, then it would be easier to allocate specific individuals to them to ensure treatment adherence. This would also prevent individuals having to engage in surreptitious behaviour to avoid being seen when taking treatment; which may not always be possible, after all, when they live closely together with other people, or when the space where they normally take the medication is invaded or occupied at the scheduled time. The alternatives to the ARV-access policy that are suggested herein may make it possible to meet the goals

suggested by the ARV-policy without infected individuals necessarily disclosing to family members, especially in cases where such disclosure could have serious negative repercussions.

University of Cape Town

CHAPTER 8

RECOMMENDATIONS FOR FURTHER STUDY

A similar study could be conducted amongst males to observe whether there is a difference in the psychological challenges that they experience when disclosing an HIV/AIDS-infected status and how this impacts on the manner in which they take their treatment. Cape Town is the first city in South Africa whose inhabitants have been provided with ARV-treatment- this may have somehow influenced participants' views of adhering to treatment as they have come into contact with a number of people who have been on treatment, have seen how effective treatment can be and may have been motivated to adhere to treatment because of this. It could be beneficial to conduct a similar study in a rural town, whose residents have just recently been given access to ARV-treatment.

Previous research has focused on participants above the age of 25, probably because individuals in that age group are more likely to join HIV/AIDS organizations, thus they are more accessible to researchers. It would however be of benefit to conduct a similar study amongst participants younger than the age of 25.

CHAPTER 9

REFLEXIVITY:

According to Steier (1991), the process of reflexivity means that the researcher must make sense of or expand on what has happened or not happened in the research study, as well as offering probable explanations concerning what has or has not taken place. Steier maintains that one of the crucial steps of making sense of how a study has unfolded, is by acknowledging the role of the 'researcher' in the production of the research. As a result, research becomes a reciprocal process in other words, it is produced by both the researcher and the participant. Steier further warns against the researcher interpreting the reciprocity that exists between the researcher itself and the participants as an opportunity to impose his or her views, instead, the researcher should allow her/himself to listen and make sense of the participants' points of view.

9.1.1) Establishing rapport with the participants:

The initiative of building an empathetic relationship with the participants began before data collection (i.e. interview sessions) started. My supervisor and I decided that I should attend the support groups, which are held by the *Luvuyolwethu* Organisation every Friday at the home of the co-ordinator. This initiative was aimed towards building an empathetic relationship with the participants. The initiative was partly motivated by the research I had conducted during Psychology with the women of the Memory Box (an HIV/AIDS organization, based in *Khayelitsha*, consisting of women who are at various stages of disclosure). I had my pilot interviews at the Memory Box offices in *Khayelitsha*. This experience exposed me to the 'typical' lifestyle or culture within this particular area. I thus thought that regularly attending *Luvuyolwethu's* support group meetings would expose me to life as experienced by the members of that group. Although they were also living in the townships, like the participants at the Memory Box, townships strata differ and are not all the same. I thus felt that my attendance at the Friday support groups would give me exposure towards the member's ways of living within this particular. and, even more importantly, help me to establish a rapport with the prospective interviewees before the actual interviewing stage. Although I am not claiming that I know everything about participants of this study or their ways of living or culture, entering their space did afford me the opportunity to learn about their lives.

The aim of this approach was to establish some kind of empathy with the organisation's members, some of whom would later participate in my research study. This approach might have influenced the actual stage of data collection in two ways, though: Firstly, it is possible that participants felt a greater sense of ease or comfort during the interview sessions, as they had 'gotten to know me' a little during the support group's meetings. Secondly, my presence during the meetings may have influenced the responses they gave during the interview session: Although I tried not to make personal comments during the support group meetings, I did however ask questions. The kinds of questions I asked during the meetings may have led other participants to reach conclusions about the kind of person that I am, thus influencing how they responded to the questions. Furthermore, even if I did not always make comments during the meetings, my mere presence may have influenced how the members presented themselves during the meetings. The opportunity of going to the location where the organization was situated, as well as the privilege of being allowed to sit in and listen as the group members spoke about the daily challenges they faced concerning living with the virus, played a role towards my attempt to approach the interview sessions sensitively by validating or accepting participant's lived realities. Although I made every effort to be sensitive in this regard, it did not prevent power difference from arising. Although it was not possible to prevent this completely, I did try to overcome it by trying to display empathy towards the participants.

9.1.2) Power differences:

Various power differences may have influenced how the interview sessions unfolded. For instance, at the beginning of each interview session, I would start by introducing myself and my research topic. I would then give the interviewee the consent form, written in *IsiXhosa*, to read by herself, discuss with the participant what was written in the consent form, then ask her to sign the consent form to signify her consent to taking part in the study.

Two challenges that I did not anticipate came to the fore at this stage: a) As all the participants had some education background, I had assumed that all of them could read, until I came across a participant who had difficulty reading. b) Similarly, I had not anticipated the fact that one of the participants could have sight problems. I had taken it for granted that all of the participants would have an un-impaired vision. One of the participants, however, had impaired vision. With regard to both participants, I

had to read and explain what was written on the consent form to them. These power differences between myself and the participants (i.e. the fact that I can read and do not have a sight problem) may have influenced the interviews. Participants may have viewed themselves as possessing a 'disability' and may have felt that I would be judgemental towards them. Such beliefs may have influenced their level of participation

A second power difference arose because of the age differences between the participants and me. The ages of the participants varied from 23 to 50 years, which influenced our conversations. For instance, I felt more comfortable when speaking to the 23-year-old participant, because we were of the same age. This led me to talk with greater ease to this participant, as I was talking to a peer. However, this particular participant may not necessarily have felt the same: although we are of the same age, the fact that I am from a different class and in tertiary education may have given her the impression that I would be judgemental of her; it is possible that she thus responded in a manner that she believed would be 'ideal' or preferred by me.

The age difference that existed between the rest of the participants and me also affected how I related to and addressed them. For instance, I addressed these participants as either 'sisi' or 'mama,' to signify that I was according them respect for being my senior. Even before the stage of data collection, the age difference had led me to anticipate the challenge of asking these participants sexually related questions, since, culturally, discussing the topic of sex, particularly with elders, tends to be considered taboo. To my surprise, however, the majority of the participants were cooperative when answering such questions. The ease in which the participants responded to questions may have been due to the fact that they had participated in various HIV/AIDS-related studies and because unprotected sexual intercourse is the predominant mode of transmission in the country, they had often been asked sexually-related questions. It is quite likely that this would have encouraged participants exposed to this kind of research to talk more freely about sexual issues. There is an alternative explanation for this, though. Like the participants, I am black, female and *Xhosa* speaking; unlike them, however, I am from a different class and I am in a tertiary institution. It is possible that this may have led some of the participants to consider me as 'dominant,' thus leading them to feel obliged to respond to my

questions, even if they were not really willing to do so and despite them being told that they had the right to refuse to respond to questions which made them feel uncomfortable. From some of the participants I did experience a degree of hesitation when discussing sexually related issues. This may have been because, although participants may have responded to similar questions in the past, because I was younger than them and because culturally they could have viewed me as a daughter, they may have felt that it was inappropriate to discuss sexual issues with me.

The fact that I was using a tape recorder to record the dialogues may also have made some of them anxious irrespective of the rapport I had attempted to establish with them, they did not really know me, and the fact that I would be keeping the tapes with their names and speeches recorded on them, may have made them uncertain how safe this information would be kept. This may have invoked a sense of anxiety amongst the participants and had an impact on how they responded to my questions.

Conducting this research made me realise that, even if the interviewer's characteristics or power differences could be considered 'superior' or 'better' than those of the interviewees, during the process of data collection, the interviewee nonetheless retains more power than the interviewer as far as data about the topic is concerned. For example, the interviewee could have provided false information or simply chosen not to respond to questions that are crucial to the study. Thus, it could be argued that the power differences that exist within the interviewer-interviewee relationship and that thus shape how research unfolds, are not static; instead, they are shared by both the interviewer and interviewee, with neither of the two having absolute power. However, certain power factors (e.g. 'race,' class, culture, age, etc.) have an influence over how the process of data collection unfolds, seeing that the above mentioned power differences and other power factors may affect the kinds of responses or explanations offered by the interviewee during the interview sessions. As Steier (1991) suggests, such power differences should, however, not deter the interviewee from asking about the questions that are necessary to investigate the particular topic, although such investigation should of course be in tune with the ethical rule of respecting the participant's choice of not responding to questions with which s/he is uncomfortable. The interviewer should thus attempt to ask the questions,

and leave it up to the interviewee to refrain from responding if s/he feels uncomfortable.

In conclusion, then, the process of reflexivity thus allows the researcher to be aware of the kinds of power differences that occur within the data collection process, as well as be aware of the blindspots that may not necessarily have been evident during the process of data collection. Bearing such factors in mind aides towards raising awareness and assists in approaching research empathetically and sensitively.

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CHAPTER 10

CONCLUSION

The ARV-policy is based on the assumption that the availability of effective ARV-medication would lessen the stigma around HIV/AIDS, thus making it easier for individuals living with the virus to disclose their status to their family members. The results from this study illustrated that, despite this, the fear of being stigmatized, which has the potential of resulting into adverse (economic, social, and physical) consequences, acted as the main reason why participants were so afraid to disclose their status to their family members and partners. Thus, it could be maintained that participant's act of maintaining secrecy about their HIV-status served the purpose of protecting themselves from the possible negative consequences that could result when an HIV/AIDS-infected status is made known to their relevant others.

This fear or anticipation of negative effects from the family members they lived with, led participants to disclose to individuals outside of their homes in order to be able to access ARV-treatment. The fear associated with disclosing an HIV/AIDS-infected status to family members and relevant others, also resulted in participants pretending to suffer from various other illnesses, as well as either going through the daily anxiety provoking process of avoiding being seen or watched every time they had to take their treatment or, alternatively, taking their treatment in the presence of their family members or relevant others, all the while fearful that the medication might be recognised as ARV-medication.

In addition, results further showed that there was a correlation between the lack of disclosing an HIV/AIDS-infected status to family members; taking treatment in secrecy and treatment non-adherence. As well as a correlation between not disclosing an HIV/AIDS-infected status to family members; taking ARV-medication in the presence of family members and treatment adherence. Furthermore, results showed that the fear of being stigmatised, due to being infected with the HI-virus, also led some of the participants to go through the inconvenience of collecting treatment and attending support groups in other areas rather than in their own neighbourhoods, all to avoid being seen and this information reaching their family members. Although participants stated that they did not have a problem with the ARV-access policy,

which would enable them to access treatment, it however appeared that the main reason for disclosure stemmed from wanting to access ARV treatment and improve their health conditions, and not necessarily because HIV/AIDS was accorded 'less shame' now that there is effective treatment, as was suggested by the ARV-policy. Such results demonstrate that irrespective of the available effective medication, HIV/AIDS continues to be a stigmatized disease and that, as a result makes it difficult for individuals living with the virus to admit being infected, particularly so to their family members.

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UMBULELO NGOKUTHATHA INXAXHEBA KOLU-PHANDO

Esi sisivumelwano sokuba mna.....ndifumene ixabiso lemali elingange
R100,00 njengombulelo ngokuthatha inxaxheba kolu-phando.

Signature.....

Date.....

University of Cape Town