

The copyright of this thesis vests in the author. No quotation from it or information derived from it is to be published without full acknowledgement of the source. The thesis is to be used for private study or non-commercial research purposes only.

Published by the University of Cape Town (UCT) in terms of the non-exclusive license granted to UCT by the author.

WOMEN LIVING WITH HIV IN SOUTH AFRICA: DISCOURSES OF
'NORMALISATION' AND FEMININITY

ANNA AULETTE-ROOT-TOYER

Submitted for the degree of Masters of Social Science in Psychology

Faculty of Humanities

University of Cape Town

2007

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 been cited and referenced.

Signature:

Signed by candidate

Date: 30/9/07

ACKNOWLEDGEMENTS

I would like to first thank Floretta Boonzaier for being my advisor. The day we met at the University of Cape Town Open Day in 2005 will always stick in my mind because I had just moved to South Africa and it was the first time I met someone in academia who was interested in the experiences of women and qualitative research. Thank you Floretta, for allowing me to pursue the type of research that I had not been allowed or encouraged to do before. I have learned so much from you over the past 2 years and I so greatly admire the work you have done in your field.

Thank you to my parents Albert and Judy Aulette. Without you I would never have had the chance to come to this country that has been so kind to me. Thanks for all of your support and encouragement and all of the late-night instant messages of encouragement and overnight editing. I miss you over here.

To my sister, Liz (E.)Aulette-Root, as much as I hate to say this, thank you for letting me test my ideas on you. I appreciate all of our fast-paced coffee-induced conversations where you helped me to clarify my thoughts and you did inspire me on occasion.

To Rashaad “Baby” Toyer, you have been so patient. Thank you for countless meals, your middle-of-the-night motivational speeches, and your unconditional love. We are going to go far together.

To my people in Detroit, especially Shae Robinson and Fredrick Thomas. You have inspired me more than you can imagine. Thank your for your years of love and support in Detroit and now, long-distance emails via internet-addiction websites.

Finally, above all I would like to thank the women who volunteered their words and ideas for this study and thank you to all of the people of that un-named support group in the outskirts of Cape Town. What you have given me is invaluable. Thank you for helping me to keep my eyes on the big picture in that HIV is not about research projects—it is about real people—it is about all of us!

ABSTRACT

Sub-Saharan Africa has the greatest proportion of people living with HIV. As of 2005, 28.5 million people in southern Africa were living with HIV and 57% of them are women (UNAIDS, 2005). As the pandemic progresses, scholarly work is produced surrounding HIV but this still remains within the confines of the hegemonic construct of HIV as a bio-medical problem. The literature does not reflect the fact that HIV is a gendered experience nor does it reflect the discourses of HIV produced by the women who are living with the virus. This study focused on uncovering the discourses of women living with HIV by conducting 15 semi-structured qualitative interviews with women living in a suburb of Cape Town, South Africa. The research was conducted within a feminist framework and the interview questions focus on women's experiences of living with HIV. The interview transcripts were discursively analysed. The analysis focuses on the context in which the women were speaking as well as the language they employed. The discourses that emerged are: normalisation through men and work, the positive and negative effects of disclosure, taking care of men and children versus abuse, and bodily changes. The findings indicate that future research must take into consideration not only the dominant bio-medical discourses of HIV, but the discourses of the very women living with the virus. In addition, the discourses of women that emerge in this study indicate the need for the global restructuring of oppressive hegemonic systems that have exacerbated the HIV problem for women as well as men, if we are to see the end of HIV as a social problem.

TABLE OF CONTENTS

Acknowledgements

Abstract

CHAPTER 1: INTRODUCTION

1

CHAPTER 2: RESEARCHING HIV

5

2.1 GENDERED HIV STIGMA

5

2.1.1 What is Gendered HIV Stigma?

6

2.1.2 Stigmatising Societal Beliefs about Women Living with HIV

7

2.1.3 Stigma and Blame

10

2.1.4 Stigmatising and Social Distancing

11

2.1.5 Women's Experiences of Stigma

13

2.1.6 Women's Experiences of Stigma and Disclosure of HIV

15

Positive Status

2.1.7 The Psychological Impact of Stigma on Women Living

17

with HIV

2.1.8 Stigma is a Barrier to Maintaining Health for Women

18

Living with HIV

2.2 THE COSTS OF HIV: CARE WORK AND SOCIAL SUPPORT

19

2.3 ARV PROGRAMMES

24

2.4 BODY IMAGE, HIV AND GENDER	27
2.5 GENDER, HIV AND GENDER-BASED VIOLENCE	30
CHAPTER 3: METHODOLOGY	35
3.1 RESEARCH DESIGN	35
3.2 FEMINIST RESEARCH, SOCIAL CONSTRUCTIONISM AND DISCOURSE	37
3.3 STUDY CONTEXT AND PARTICIPANTS	39
3.4 PROCEDURES AND METHOD	42
3.5 REFLEXIVITY	45
3.6 ANALYSIS OF QUALITATIVE DATA	51
3.7 ETHICAL CONSIDERATIONS	54
CHAPTER 4: ANALYSIS AND DISCUSSION	57
4.1 BEING NORMAL THROUGH MEN AND WORK	58
4.1.1 Working is Normal	58
4.1.2 Having a Man is Normal	65
4.2 DISCLOSURE FOR BETTER OR WORSE	70
4.3 THE COMPLEXITIES OF CARE WORK VERSUS GENDER-BASED VIOLENCE	85
4.3.1 Doing Care Work for Children	98
4.4 A WOMAN'S BODY	105
4.5 SUMMARY: DISCOURSES OF FEMININITY AND NORMALISATION	121

CHAPTER 5: CONCLUSIONS	123
5.1 DISCOURSES OF NORMALISATION: WORK AND MEN	123
5.2 DISCOURSES OF DISCLOSURE	126
5.3 DISCOURSES OF CARE WORK IN VIOLENT SITUATIONS	128
5.4 DISCOURSES OF WOMEN'S BODIES	129
5.5 THEORETICAL AND METHODOLOGICAL IMPLICATIONS	131
5.6 RECOMMENDATIONS FOR PRACTICE AND POLICY	135
5.6.1 Gender Mainstreaming in HIV	135
5.6 STUDY LIMITATIONS AND FURTHER RESEARCH	138
REFERENCES	140
APPENDIX A	151
INTERVIEW SCHEDULE	
APPENDIX B	154
INFORMED CONSENT FORM	

CHAPTER 1: INTRODUCTION

For the past 24 years HIV¹ has expanded rapidly throughout the world affecting people in all nations and in all walks of life. The spread of HIV, however, has not been uniform as some populations are more vulnerable. As Piot (2001) argued, the pandemic, “is fuelled by the forces of inequality, social exclusion, and economic vulnerability” (p. 609). Sub-Saharan Africa has the greatest proportion of people living with HIV; as of 2005, there were 25.8 million people in this region living with HIV (UNAIDS, 2005). Furthermore, HIV has been increasingly, disproportionately infecting women as the pandemic continues in southern Africa as well as other nations (UNAIDS, 2000). Of the 25.8 million infected with HIV in sub-Saharan African, 57% were women, which is a proportion that has been growing rapidly for the past decade (UNAIDS, 2005). More specifically, in South Africa, Shisana and Simbaye (2002) found in their report for the Human Sciences Research Council (HSRC) that women aged 25-29 have an HIV prevalence rate of 28%. In fact, according to a report released by Statistics South Africa (2005), ‘HIV disease’ as a cause of death ranked in the top ten causes of death for South African women in 2005, but it did not rank in the top ten for men. These statistics illustrate quantitatively, just how great a problem HIV has become for the world as a whole, for South Africa, and for women in particular.

¹ The terms “living with HIV” and “HIV positive” are used when possible throughout this thesis instead of “HIV/AIDS” because the term “AIDS” has become associated with stigmatising images of disease and death. The term “HIV” used without the accompanying “AIDS” encompasses the whole range of people living with HIV and who are asymptomatic as well as those people who have experienced what is referred to as “AIDS-defining illnesses.” Furthermore the terms “AIDS” and “AIDS-defining illnesses” are arguably obsolete in the age of ARV therapy where it is now possible to go from being gravely ill to having a nearly undetectable viral load and a CD4 count within the normal range, which are also markers used to indicate the stage or progression of the illness. In addition, the stage or progression at which the women’s HIV infection is at is not relevant in the context of this study.

As the HIV 'problem' has grown, international, national, and local organisations are seeking ways to support HIV positive people in order to stop the spread of the virus and to diminish the health problems for those who are already HIV positive. HIV is an escalating problem in most parts of the world and for women in particular. It becomes imperative, therefore, for women to receive the most effective social and psychological support possible in order to facilitate improvements in their own health and to safeguard the community from worsening conditions that result from HIV. The information gathered in this study is of value to the improvement and restructuring of programmes and policy in the communities of South Africa as well as programmes and policy with similar goals being introduced in other parts of the world.

For a crisis as great and widely written about as HIV, limited types of research have been done on the problem, specifically as it is related to the lives of the women living with the virus. In fact, most of the existing research has been generated within the confines of the Western hegemonic construct of HIV as a biomedical problem that can be 'combated' through education of the 'ignorant masses', medication, and vaccination. In all of its powerful dominance, the discourse of medicine and education has pushed aside the fact that HIV is a global social problem. Hegemonic power structures have an agenda when it comes to HIV, for HIV is an industry that is fueling capitalist economies through the research and pharmaceutical industries which is exemplified in cases like the one in which the pharmaceutical company Novartis took legal action against the Indian government because of its loss of profits due to the fact that India is the largest exporter of generic ARVs in the world (Oxfam, 2007, August). In addition, in not dealing with and profiting from the HIV problem, these power structures benefit in that HIV infection

maintains the status quo through further oppression of already marginalised groups of people, namely women. The disproportionate rate at which women are being infected with HIV suggests that gender inequality plays a role in the progression of the epidemic. As feminist researchers, part of our duty is to shed light on the issues and people that have been shrouded and silenced.

This research aims to uncover women's experiences of living with HIV by conducting a discourse analysis of the transcripts obtained through qualitative semi-structured interviews. The research is framed by critical feminist theory as a way to understand the experiences of women. Feminist theories maintain that the world is not the same for women compared to men--social relationships and social institutions place women in subordinate positions, and women's experiences and oppression are a result of the patriarchal way in which societies are arranged (DeVault, 1999). Feminists assert that gender inequality and gender injustice make it essential that we listen to the voices of women living with HIV in order to ensure that we hear the realities and that we begin to address and take action concerning their needs as well as the needs of a broader society contending with HIV in an effective manner. This research explores and provides an analysis of the gendered experience of HIV in South Africa by examining the discourses of women who are HIV positive. More specifically, the objectives of this research are to:

- Uncover women's experiences of living with HIV in light of the gender inequalities women face, by asking women themselves.
- Better understand the issues women face that may have lead to their exposure to the virus as well as the problems women face after the discovery of their positive status.

- Provide an analysis of women's experiences of living with HIV that is relevant and points towards the areas in women's lives that require action to effectively provide psycho-social support for women living with HIV.

The research begins with a review of the literature on HIV and the issues that are pertinent to women living with the virus in chapter two. Three important areas of HIV research are identified: gendered HIV stigma; the costs of HIV: Care work and social support; ARV programmes, body image, HIV and gender, and HIV and gender-based violence. Chapter three is an outline of the methodology and research design employed and drawn upon in the study. In chapter four, the analysis and discussion of the investigation unfold in the emergent discourses of being normal through men and work; disclosure for better or worse; the complexities of care work versus gender-based violence; and a woman's body. The conclusions and recommendations for further research as well as a call for the restructuring of the hegemonic, patriarchal system that is responsible for the social problems resulting from HIV are presented in the fifth and final chapter.

CHAPTER 2: RESEARCHING HIV

This thesis seeks to explore the gendered experience of HIV in South Africa by examining the discourses of women who are HIV positive. The literature on HIV is a vast landscape of research that for the most part, examines HIV within the confines of the virus as a bio-medical issue. However, there are scholars who have investigated HIV as a social problem that has its root in issues of race, class, and gender, for these issues are all inextricable. The connections between gender, in particular, and HIV are highlighted in five important areas of HIV research: stigma, care work, ARV programmes, body image and gender-based violence. This literature review looks into each of these areas seeking to find both what elements of these four issues have been uncovered as well as what remains to be learned.

2.1 Gendered HIV Stigma

Stigma is perhaps one of the most well-researched areas of HIV and it has been identified as a highly gendered phenomenon. There is no escaping the stigmas that are attached to HIV but peoples' experiences of stigma differ across many variables including gender. Women and men are stigmatised differently in regard to the extent to which they can be blamed for their actions that led to their HIV positive status. The blaming that occurs is linked to gender and reproductive roles that define 'good' and 'bad' behaviour and 'wrongdoings', especially sexual wrongdoings which are different for men and women (Lorber & Moore, 2002). Furthermore, the reason for the staying-power or escalation of gendered HIV stigma may stem from the fact that all different

kinds of stigma are inextricably linked to a marginalisation or ‘othering’ of one kind or another.

2.1.1 What is Gendered HIV Stigma?

In order to understand the many aspects of HIV stigma, it is helpful to understand how it is defined. According to Goffman (1963, p. 15), one of the first scholars to study stigma, stigma can be defined as the belief that, “people who possess a characteristic defined as socially undesirable acquire a ‘spoiled identity’ which then leads to social devaluation and discrimination.” His definition notes the relationship between stigma and discrimination. In their HIV stigma research for the HSRC in South Africa, Deacon, Stephney, and Prosalendis (2005) further clarify the link between stigma and discrimination by saying that HIV stigma is the negative *ideas* people believe about people living with HIV and discrimination is the *actions* that are taken that unfairly disadvantage people living with the virus.

Classical theorists such as Goffman (1963) did not link stigma to a larger social context. More recent scholars such as Deacon et al. (2005) focus on this relationship noting that, stigma and subsequent discrimination, “[have] the effect of reproducing relations of social inequality that are advantageous to the dominant class, these forms of stigmatisation are functional in the sense that they help maintain the socio-political status quo” (p. 17). In terms of HIV, stigma is a powerful ‘othering’ force that has an impact on who gets blamed for the disease, who is allowed access to treatment, and how women living with the virus experience their lives and themselves. Stigma then, is a tool of power that helps to maintain the status quo by ensuring that only certain people—those in

less powerful positions--are blamed for problems and existing relations of power are kept in place. Since gender is a system of power, stigmatising women who are living with HIV is a useful ideological tool to maintain existing gendered power relations.

2.1.2 Stigmatising Societal Beliefs about Women Living with HIV

Seidel (1993) has studied how HIV/AIDS discourse, the way in which society talks about HIV, can contribute to stigma. She speaks about the medical, medico-moral, developmental, legal, ethical, and activist discourses that operate in sub-Saharan Africa. She asserts that medical and medico-moral discourses are the dominant forms of HIV stigma discourses.

Medical discourse refers to messages from large medical authorities such as the World Health Organisation (WHO) that invent terms like 'high risk group' which end up stigmatising people who are identified with particular groups within a society. Women are one such group. The term, high risk group, refers to highly studied (when it comes the HIV pandemic) communities of people like women of colour, intravenous drug users, and sex workers. This term stigmatises and 'others' all women as well as the women in those specific, already marginalised communities, making it seem like there is a unique elevated rate or risk of HIV infection in these people as opposed to groups of people like heterosexual men or white people in general. In reality, actual risk is associated with particular behaviours, not specific communities of people. The discourse, however, identifies certain groups as high risk thereby allowing them to be blamed for their infection and the spread of infection into the dominant 'innocent' groups of people.

Many people have been categorised as ‘other’ and subsequently stigmatised in this way in discourses surrounding HIV. For example, another term, “Pattern II countries” creates stigma by constructing “African AIDS” (Seidel, 1993, p. 177). This terminology makes it appear as if HIV manifests itself as a completely different type of disease on the continent of Africa as opposed to the ‘safer’ type of HIV found in North America and Europe². These terms lead to the stigmatisation of both women and men living in Africa as well as furthering the racist way in which black and/or African sexuality had been constructed by the West as ‘primitive’ and ‘deviant’ (Austin, 1990). This stigma, which operates in medical discourses, “has profound implications for funding and for international solidarity. It is a new, very authoritative and sophisticated variety of the discourse of control and exclusion, which, because of its medical and scientific stable, passes as neutral and non-ideological (Seidel, 1993, p. 177).

According to Ratele and Shefer (2002), another means by which HIV stigma has been constructed is through the idea of constructing, blaming, and othering “sexual deviants” that are in actuality members of already marginalised groups. Numerous myths about ‘who’ started the ‘AIDS pandemic’ have created stigmatised groups. For example, the idea that HIV was initially identified in gay men in the USA fueled homophobia and the idea that AIDS was a disease that would punish the atrocity of gay sexuality (Ratele & Shefer, 2002). Similarly the theory that the beginnings of the pandemic mysteriously started in Haitian people led to the belief by the US Center for Disease Control (CDC) that Haitians were inherently and mysteriously susceptible to HIV infection which lead to

² There are two distinct HI viruses that are genetically different. “African AIDS” refers to HIV-2 that is said to be largely confined to West Africa (Kestler, Medley & Horn, 2001). HIV-1 is the virus that is most common in North America and Europe. Ironically, according to Wilson, Naigoo, Bekker, Cotton & Maartens (2004), HIV-2 is less pathogenic and it is in fact HIV-1 that is responsible for the global pandemic.

the subsequent quarantine and detention of Haitian immigrants (and anyone 'resembling' a Haitian immigrant for that matter) in the United States (Farmer, 1992; Sessions, 2001). This story reinforces the racist link between sexual deviance, promiscuity and being black (Collins, 2000).

And there is of course, the theory that AIDS started in Africa as a result of humans coming into close physical contact with monkeys infected with simian immunodeficiency virus (SIV), a virus similar to the HI virus which purportedly crossed species and mutated into the virus that we now know as HIV (Chirimuuta & Chirimuuta, 1989; Gallo, 2006). This story galvanises the global racist assumptions about the continent of Africa and of black people in general as having 'untamed' or deviant sexual practices. Over the years these ideas regarding othered or marginalised groups of people who fueled the pandemic has lead to the subsequent stigmatisation of sex workers, drug users and in general, poor women of colour.

In addition to these global stories fueling stigmatisation of people who are HIV positive, local beliefs have created stories that supplement them. According to a study by Kalichman and Simbayi (2004), a particular stigma surrounding people living with HIV occurs in several South African townships and other rural areas on the continent that stems from the belief in traditional supernatural beliefs. Some South Africans believe that the ancestors and God send illness or withdraw protection from illness because a person has done something wrong in their life (Kalichman & Simbayi, 2004). Illness is seen as an indicator of wrongdoing, therefore the person should be considered dirty, and they should be ashamed and avoided. Incidentally, this particular type of stigma is part of the

fundamentalist Christian myth in the United States that claims that HIV is 'God's punishment' for being gay (Seidel, 1993).

2.1.3 Stigma and Blame

Over the years, women have directly and indirectly been referred to as vectors of HIV. Women being constructed as vectors can be seen in the programmes that have been established in attempts to slow the spread of HIV. According to Seidel (1993), Christian groups often establish HIV education and intervention programmes that serve to further stigmatise women. Their interventions center on the value of chastity, abstinence and staying faithful. These programmes have been promoted all over the world, including South Africa. In addition, some communities in South African have created other interventions such as virginity testing where girls and young women are 'tested' for their virginity by older women community members (Hoosen & Collins, 2004). If these girls and young women pass the test, it is thought that they will be empowered to abstain from sex before marriage, curbing the spread of HIV. Virginity testing, however, has been banned by the South African government as it poses a human rights violation against girls and young women. Furthermore it does not test for HIV and it places all the blame and responsibility for the spread of HIV in the hands of women and girls. The same could be said of other efforts to place control of HIV prevention in the hands of women for example microbicides and female condoms. However, according to Mantell et al. (2006), the result of the introduction of women-controlled methods of HIV prevention has been a paradox in that the same structures that are barriers to HIV prevention in women also shape the lack of acceptability of these methods. So, even when the burden of

responsibility of prevention is unfairly placed on women, it is still impossible for women to exert real control over the matter. Furthermore, studies of the sexual practices of young adults in South Africa show that boys and young men are encouraged to have numerous sexual experiences as a 'natural' part of manhood (Reddy, 2005). These ideas of natural conduct for men and 'good conduct' for women create stigma for women living with HIV because they endorse the idea that women who 'misbehave' wind up HIV positive and are the ones that spread the virus to others.

Another way in which women have been constructed as vectors of HIV is through the idea of reproductive responsibility. In their study of women's experiences of stigma, Lekas, Siegel and Schrimshaw (2006) report that HIV positive women experience intense stigma from the medical community and society as a whole when they make the decision to have children. Women in the study felt as though they were being punished for having become infected because they are discouraged from becoming mothers even though there are now effective ARV measures available to women who are living with HIV and want to have children. This kind of stigma becomes even more problematic in the context of South Africa because studies have shown that women's fertility is associated with a positive social status (Strebel, 1995). Being HIV positive and childless may in fact be a double blow to some women.

2.1.4 Stigmatising and Social Distancing

Blame is not the only form of stigmatisation. Social distancing is a second form. Adam and Sears (1996) found that women living with HIV have a unique set of problems that isolates them from the rest of society. This isolation begins in the form of beliefs

within a society or a certain community about women living with HIV. For example, isolation occurs when family and community members express a fear of being in contact with women who are HIV positive, lest they become infected. This form of distancing is illustrated by family members physically separating themselves from those who are HIV positive and excessively disinfecting items the person has come into contact with. Leka et al. (2006) refer to these kinds of behaviours as “hygienic degradation acts” (p. 1180). Separating eating utensils, clothing and cosmetics as well as keeping a distance from people living with HIV for fear of contagion can be documented in numerous studies on HIV and stigma and they stem, in part, from persistent erroneous beliefs people have about HIV transmission (Leka et al., 2006; Li et al., 2006; Castle, 2004).

Hoosen and Collins (2004) point out that although most research claims that the majority of people are now aware of the routes of HIV transmission, there is strong evidence to suggest otherwise. In their research in South Africa, they found that some people in their study were unsure about or inaccurate in their knowledge of HIV transmission and there were even those who claimed to have never heard of condoms. This lack of basic HIV knowledge shows up again in the research done by Castle (2004) in Mali. In her research, Castle (2004) spoke to children, teachers, leaders, and parents in a community about HIV stigma. She found that children and parents especially, and teachers and leaders to some extent, exhibit “great confusion” (p. 6) about how the virus is transmitted. Their beliefs ranged from thinking that the infection spread by defecating and urinating in the same place as others, to thinking that HIV started when girls were paid to have sex with white people’s dogs. These beliefs go hand in hand with the beliefs that people living with HIV are dirty and disgusting and should be avoided. Castle (2004)

also found that the children in her study felt that people living with HIV should be separated from society and deserved little compassion because,

By having sexual relations, the person is viewed as having transgressed the social norms imbued to this group of young people which emphasise abstinence before marriage or faithfulness within it and thus appear to be seen as having brought the illness upon themselves (p. 13).

This attitude is especially stigmatising to women living with HIV as it is often women who are the ones held responsible for chastity and faithfulness in marriage (Castle, 2004).

2.1.5 Women's Experiences of Stigma

HIV stigma is complex and layered in the way that it is experienced and can ultimately lead to lost opportunities, social isolation, and the internalisation of stigmatising ideas (Fife & Wright, 2000). A person living with the virus may have personal experiences of being stigmatised or have been outright discriminated against because of their status. A person can also perceive stigma when they overhear others talking about or discriminating against *others* living with the virus (Lekas et al., 2000). In either case, these stigmatising experiences in addition to experiences and beliefs a person may have had prior to testing positive for HIV (Fife & Wright, 2000), are likely to lead to internalisation.

Internal stigma, also known as felt stigma, self-stigmatisation, and perceived stigma, has been identified in the literature as a type of HIV stigma (Deacon et al., 2005; Lekas et al., 2006; Visser, Makin & Lehobye, 2006). Although there is some debate as to

how these terms should be conceptualised in regard to whether they are types of internal stigma or “linked processes” of internal stigmatisation (Deacon et al., 2005, p. 21), they can be understood as the process by which people living with HIV start to believe the negative ideas about people living with HIV. These beliefs may come in the form of the internalisation of negative feelings about contracting the virus, feeling ashamed and condemning themselves for their own sexual practices or misfortunes and the harm that the virus is causing in their lives. In addition, internal stigma may lead to people believing that because they are HIV positive, they are unclean, bad, and are being punished for their ‘careless behaviour’ (Nyblade, 2006).

Self-stigmatisation is even more of a problem for women because of the abundance of stigmatising beliefs surrounding women’s sexuality (Lorber & Moore, 2002) including the notions of ‘good women’ being sexually passive and the perpetuation of the racist link between sexual promiscuity and blackness (Collins, 2000) even without the added factor of being HIV positive. In addition, women may internalise HIV stigma because of the discourse of women as vectors who are responsible for spreading the disease (Ratele & Shefer, 2002). Furthermore, their perceived reproductive roles cast women who are HIV positive and have children as vertical vectors of the virus in mother-to-child transmission (Lekas et al, 2006; Visser et al., 2006). Internal stigmatisation is further detrimental to women living with HIV because it prevents women from seeking help in the forms of social and medical support and it quite possibly leads to women punishing themselves for having become HIV positive (Fife & Wright, 2000).

2.1.6 Women's Experiences of Stigma and Disclosure of HIV Positive Status

When anyone receives a positive result on an HIV test, she or he faces the dilemma of whether or not to tell anyone. Disclosure is an important issue because it may determine whether a person seeks treatment for HIV/AIDS or not (Klitzman et al., 2004). In order to receive treatment (if it is available at all) a person must at the very least, disclose their status to healthcare workers. Disclosure must also take place in order for a person living with HIV to receive social, emotional, and adherence to treatment support (Klitzman et al., 2004). The literature shows that stigma is oftentimes a barrier to disclosure especially for women. However, some research shows that stigma may not be a barrier to preventing women from taking care of their health.

Women in Burkina Faso, like many women all over the world, have weak economic status, low levels of education, begin having sex with older men at an early age, rarely use condoms, and are submissive to men (Issiaka et al., 2001). Despite these problems, in Issiaka et al's study, most of the women who are living with HIV say that their number one concern is their health. This implies that they are more concerned with their health than they are with the tasks of disclosing their status and dealing with stigma. The women living with HIV in this study who, at first, decided not to disclose and then changed their mind say that their primary fear was that their partner would reject or abandon them or think that they had been unfaithful. However, upon disclosure, the most common reaction from partners was that of indifference. In other words, stigma in Burkina Faso was not as important as the women had feared and in their own view of their HIV status, health problems were more important than being stigmatised.

Another study conducted in the United States had similar findings. Kimberly, Serovich, and Greene (1995) interviewed five women living with HIV who had already disclosed their status to friends and family. Two of the women stated that they were not so much concerned with stigma as they were with the personal situations of the recipients of their disclosures. These two women wanted to delay disclosure to their mothers because their mothers were suffering from their own illnesses and they did not want to upset them. While some of the women in the Issiaka et al. (2001) and Kimberly (1995) studies and did not find stigma to be a large barrier to disclosure, other women living with HIV do.

Many of the women in the Burkina Faso study by Issiaka et al. (2001) did express that stigma was indeed a barrier to disclosure. The women in this study who did not disclose, were worried about rejection, abandonment, being accused of unfaithfulness, and withdrawal of financial support from the family because they may not want to invest money in someone who they believe is going to die soon. Some women were worried about a reaction of violence even though the women from Burkina Faso did not report violent reactions from male partners as they do in the USA, Kenya, South Africa, and Rwanda (Rothenberg, 1995; Seidel & Ntuli, 1996; Temmerman, 1995; Van der Straten, King, Grinstead, Serufulira & Allen, 1995). Several women in the Kimberly et al. (1995) study disclosed only to close friends and family for fear of being fired, being evicted, losing health insurance, and losing custody of their children. In summary making the decision to disclose is not easy, for it is difficult to gauge the type and extent of the stigma that one may experience as a result.

2.1.7 The Psychological Impact of Stigma on Women Living with HIV

There are psychological implications of stigma whether a woman is experiencing self-stigma, stigma in a community, or stigma by a social institution. It is important to look at the psychological problems that people living with HIV experience because “psychological processes” contribute to worsening physical health in people who are living with HIV (Brief et al., 2004, p. 6). In fact, Hader, Smith, Moore, and Holmberg (2001) argue that the higher presence of symptoms of depression in women living with HIV may be associated with their higher levels of morbidity and mortality as opposed to men. At the very least, the mental health effects of living with HIV lead to a poorer quality of life (Tostes, Chalub & Botega, 2004) and will worsen the experiences of women who are already a marginalised community (Lorber & Moore, 2002).

According to Fife and Wright (2000) people living with HIV in the United States experience more feelings of stigmatisation than people with cancer. Among the HIV positive people in their study, women experienced even more feelings of stigmatisation than did men. They claim that women feel more social isolation because they have less support due to their fear of the consequences of disclosure, for example losing custody of their children. Because of this isolation, women end up internalising these feelings, which results in poorer self-esteem (Fife & Wright, 2000). Similarly, in a study by Tostes et al. (2004) in Brazil, it was found that women who are living with HIV are more likely than men to experience symptoms of depression resulting from stigma. Because of the nature of HIV ‘disease’ in that it is a social problem and the nature of HIV stigma, women are especially at risk for psychological problems that are a result of living with HIV.

2.1.8 Stigma is a Barrier to Maintaining Health for Women Living with HIV

Probably the most important step a woman who is HIV positive or is in danger of becoming HIV positive for various reasons can take for herself is to pay attention to her physical health. This means being able to access and use condoms and not being in situations where sexual violence or coercion are possibilities. These may sound like relatively basic steps, but according to the literature, stigma often stands in the way of women who are trying to attain these goals.

Seidel (1993) states that in Uganda, as well as in other countries, it is believed that making condoms available to women encourages promiscuity and it is considered taboo for women to even discuss their use. Instead of allowing access to condoms, Uganda has promoted chastity and high bride prices, both of which reinforce the stigma against women who are living with HIV. Mill and Anarfi (2002) point out that for some women in Ghana, condoms are available, but that women who have condoms or ask their partner to use one may be seen as 'loose' or 'dirty.' When there is a stigma against women using condoms, it is difficult for women to protect themselves against becoming infected or being repeatedly re-infected with HIV or other STIs.

HIV stigma is a force which creates barriers against accessing proper support and healthcare for people living with HIV. It is not only an outside force, but it is a force from within and many people must battle with their own internal stigma, especially women who must deal with a particularly gendered form of HIV stigma. The literature on HIV exposes stigma in its many permutations, however HIV stigma has yet to be widely written about in terms of how it is made possible. It seems that the literature on HIV stigma has neglected to adequately uncover and explain the powerful forces that

contribute to the maintenance of stigma as a primary problem for those living with HIV. However, HIV stigma is only one of the issues that have been written about as pertinent to the lives of HIV positive women. In the next section, we will see how doing care work and providing as well as receiving social support is a struggle as well.

2.2 The Costs of HIV: Care Work and Social Support

A second area of scholarly work on the connection between gender and HIV is around the question of care work. The literature strongly supports the idea that people who are living with HIV need social support in one form or another. The term social support is used in a number of different ways in the literature so it is not easy to define. Green (1993) offers a general definition of social support in the context of illness as “(i) the existence, quantity and type of interpersonal relationships (network structure or social interaction), (ii) the functional content of these relationships (emotional, psychological, tangible or informational support), and (iii) the perceived quality or adequacy of this support” (p. 90). Because the term is a general one, it is clear that there are lots of ways in which people living with HIV receive social support (if they are indeed receiving any at all).

People with chronic illnesses such as HIV are sometimes able to receive social support, which is a form of care work, from friends and family members (Folkman, Chesney & Christopher-Richards, 1994; Green, 1993; Schwarzer, Dunkel-Schetter & Kemeny, 1994) through support groups (Friedland, Renwick & McColl, 1996), and social workers and healthcare workers (Kelly & Mzizi, 2005). Good social support, regardless of the source, is said to have a buffering effect against the anxiety, including stigma, in

people living with the virus (Servellen & Lombardi, 2005). Friedland et al. (1996) report that certain forms of social support are positively related to quality of life. There is an abundance of evidence that suggests that people who receive adequate social support from their health-care provider alone, show better adherence to ARVs and other medication (Bakken et al., 2000; Catz, Heckman, Kochman & DiMarco, 2001; Chesney, 2003). Some studies have even found that people living with HIV who receive what they consider adequate support, have higher CD4 counts (Ashton et al., 2005; Theorell et al., 1995) and a longer survival rate (Ashton et al., 2005). It is imperative that proper forms of social support are provided to people living with HIV especially because of the fact that HIV is more than an illness; it is a social problem. Because of this, care and social support have to be understood in their complexities including the complexity of gender.

As the prevalence of HIV, particularly for women, increases, the need for care and social support increases. These care and support systems, however, are oftentimes inadequate. In a study conducted by Kelley and Mzizi (2005) about the limitations of ARV programmes in South Africa, they found that by simply making support groups available to people living with HIV is not enough. There are circumstances which make it difficult or impossible for some people to attend such meetings. Barriers in accessing care and support are varied and many. They include forms of HIV stigma, the inability to afford transport to meetings, and some specific social inequalities women face that prevent them from giving and receiving proper social support and general care.

Social support and care-giving for people living with HIV is costly for most governments, especially in sub-Saharan Africa where the HIV prevalence is high and finances are low due in part to debt to and failed promises of aid from the World Bank

(Oxfam, 2007, February). Inevitably the burden of care work shifts from governments that cannot or will not finance it, to the women of each particular country. In fact, according to the UNAIDS initiative, The Global Coalition on Women and AIDS, 90% of home care is provided by women (UNAIDS, 2005). The women providing the care for people living with HIV are mothers, grandmothers, and girls (UNAIDS, 2005). These women may be family members, nurses, NGO workers or community members and they may be living with or without the virus. And although this work is vitally important, it is taxing—even to the detriment of these women and above all, it is with very few exceptions, unpaid.

In her study on gender and HIV, Urdang (2006) is critical of some of the social support systems in existence in southern Africa. She states that the care economy (including social support) for people living with HIV is 90% home-based and that the burden of responsibility for this care is disproportionately placed on women who may also be living with HIV themselves and who are financially strapped. Urdang (2006) also points out that even some of the more formal or organised care and support programmes are, “organised around the assumption that nurturing is women’s role and thus implicitly support patterns of female exploitation, even abuse” (p. 167). As women (who are often HIV positive themselves) struggle to provide care for family and community members living with HIV, they find themselves in more and more dire financial circumstances because of the increased household costs due to HIV including increased healthcare costs, more expensive foods, transport to and from support groups and clinics, and inevitable burial costs (UNAIDS, 2005). As the financial situation worsens, women seek

to find ways to earn money even if they are to the detriment of their own health, including sex work.

As it is explained by Dunkle et al. (2004) in their study conducted in Soweto, South Africa, transactional sex is a form of sex work in which the worker (usually a woman) does not identify as a sex worker. This form of sex work is a common way and quite possibly the only way in which women that are in dire need of money or other resources acquire these things. Because women who are care-givers to themselves, their family, and community members who are living with HIV are many times struggling to afford basic resources (UNAIDS, 2005), we could surmise that these care-takers may also be forced to resort to transactional sex to support themselves and the ones they care for just as the women (who were likely to have been doing care work) were shown to do in the Dunkle et al. study. Because of the desperate situation these women are already in, it is nearly impossible for them to negotiate condom use for various reasons. One reason may be that men who are engaging in the exchange of sex for money, gifts, or other greatly needed resources may offer women more money for not using a condom—an offer which someone in great need, may not be able to turn down (Hallman, 2005). Not only is this a risky situation in that transactional sex has been linked to gender-based violence (Dunkle et al., 2004), but that it leads to HIV infection and re-infection in women, creating an even more daunting downward spiral. In addition to the women who provide care work and social support and who may or may not be living with HIV themselves, there is the issue of children as ‘AIDS orphans’ and the care work that they need as well as provide.

UNAIDS, UNICEF & USAID (2004) estimates that there were 2 million children (under the age of 14) living with HIV in sub-Saharan Africa at the end of 2004. In addition, UNAIDS (2005) estimates that there are about 12 million children (under the age of 18) in sub-Saharan Africa who have been orphaned because of AIDS. 'AIDS orphans' is a term that has been disputed in the literature (Jones, 2005) as it is arguably inaccurate because it has been documented that most 'orphans' in sub-Saharan Africa live with a grandparent (UNAIDS, 2005) or foster family (Jones, 2005). The term 'AIDS orphans' is also dangerously inaccurate in that it ignores other forms of orphanhood and the other children (orphaned or not for various reasons) in the households that take in children whose parents have died as a result of HIV. This omission is dangerous because the more children in a household that is most likely poor to begin with, the thinner the resources for children in that household are spread (Jones, 2005). Ultimately when it comes to funding and policy, categories have to be delineated so that the resources might reach their target groups of people.

There is an important gendered dimension in terms of care work and children who are affected by HIV. Not only do women pay the cost of care for HIV, girls do too. In a study in Zimbabwe, Mushunje (2006) points out that when women living with HIV and doing care work fall ill, it is the girl child who usually takes over. When a girl's parents die as a result of HIV, not only does she suffer the tremendous grief of the traumatic loss, she must also take on the burden of caring for the other children in her household. According to a study of Zimbabwean households by Nyamukapa, Foster and Gregson (2003), girls in this situation are the first to drop out of school to become the sole breadwinner when she and her siblings are orphaned because of AIDS. These girls

lose access to education in order to care for their family, some of whom may be living with HIV (Squire, 2007). When faced with this task, girls are oftentimes forced and essentially locked into transactional sex because they do not have income-generating opportunities elsewhere. In addition to being vulnerable to gender inequalities in terms of condom negotiation, it could be said that these girls are even more vulnerable to becoming infected by HIV because of their youth in that they are even less able to negotiate condom use and physiologically, they are more vulnerable to infection.

Care work is a massive burden economically, physically and emotionally. This work entails caring for adults as well as children who may be living with HIV and the care workers themselves may be living with the virus as well. The literature has shown that the weight of this burden unjustly falls on the shoulders of women and girls and with dire consequences. Where care work and social support constitute the majority of the care that people living with HIV perform as well as receive (if they receive support at all), there are medicinal tools that also have the potential to provide some kind of care.

2.3 ARV Programmes

ARV medications and rollout programmes have become relatively more available in certain countries over recent years. In fact the Antiretroviral Treatment Protocol (Provincial Administration Western Cape, 2004) for the Western Cape, South Africa was released in 2004 and Lekas et al. (2006, p. 1165) in the United States, refer to the year 2000 and beyond as “HAART-era” (Highly Active Antiretroviral Treatment). Although more effective ARVs (HAART) are increasingly more available, the issue of ARV treatment is a complex one.

There have been convincing arguments for and against the implementation of ARV rollout plans, especially in South Africa where HIV activists have been vocal in the international arena on issue. Seidel (1993) identified an activist discourse that asserts that people of African countries have rights and benefits when it comes to drug testing and also that people have rights and access to knowledge (and treatment). Only a few years ago, some HIV activists in South Africa as well as people in government were vocal about their skepticism regarding the efficacy and safety of ARVs and questioned whether they were yet another deadly experiment the West was conducting in Africa. Criticisms of South African Health Minister Tshabalala-Msimang's endorsement of foods like garlic and lemon juice rather than ARVs for the treatment of HIV was well publicised after her speech at the International AIDS Conference in Toronto in 2006 (Lewis, 2006, August). More recently, the skepticism has been waning as people in countries who previously did not have access to ARVs are seeing the real and positive effects of the drugs. The Treatment Action Campaign (TAC), the most vocal campaign in South Africa for the rights and treatment for people living with HIV and for the prevention of new infections, asserts that it is the right of people living with HIV to receive access to ARVs in a timely manner. The TAC posits that it is a breach of the South African Constitution and of human rights that all persons living with HIV do not have access to ARVs as of yet (Treatment Action Campaign, 2007, April). In addition the TAC endorses the International AIDS Vaccine Initiative (IAVI) trials currently underway in South Africa. And although increasing numbers of people are demanding ARV treatment and vaccines, with this demand comes a cost that has to be repaid to the West. Pharmaceutical companies do not spend much money on developing drugs and vaccines that target the

poorest nations in the world. And when those companies do spend money on the development of drugs and vaccines to combat HIV, it is the people of those poor nations who have to endure the human drug trials many times to their detriment (Smitt et al., 2006; Swartz & Kagee, 2006). Despite some positive change, the ARV struggle remains in that most people still do not have access to these still relatively inconvenient and expensive medicines and if they do, many are unsure and fearful about what these pills are doing to their bodies (Pound et al., 2005). There is also the practical problem of side-effects from ARVs like severe dizziness and nausea that can last up to several months preventing women from taking care of their small children. To make matters worse in South Africa specifically, there is the issue of a person having to choose between social disability grants and ARVs.

According to a report published by the South African Department of Social Development (2006), South Africans who cannot work because of a disability, including those due to HIV, are eligible for social disability grants. Although this grant is not enough to live on considering the increasing cost of living in South Africa and especially in Cape Town, it is still a grant that many people living with HIV have come to depend on. The problem with these grants is that they do not mesh with the ARV rollout plan in South Africa. This is because as a person living with HIV becomes healthier due to the commencement of ARV therapy, they become ineligible for this grant. This creates a real quandary for people living with HIV (Hardy & Richter, 2006). On one hand, a doctor may tell a person who has become ill because of the virus, that their viral load and most importantly, their CD4 count is at the point at which there is a need for ARV therapy³.

³ The point at which a person is in need of ARV medication is still up for debate in the medical literature. Some doctors believe that commencement should depend on the overall health of a

On the other hand, if a person has come to rely on a social disability grant to support their family, they actually run the 'risk' of improving their health to the point that the Department of Social Development deems the grant unnecessary (Hardy & Richter, 2006). This causes further problems for women in particular because they are, as explained above, responsible for caring for and supporting the people in their household. For many women, it may seem that there is really no choice to be made between their own health and the daily needs of their children and other people they are supporting. This problem often leads to non-adherence and the subsequent downfall of physical as well as emotional health. The responsibilities of women for care work causes them to face an ironic and tragic dilemma between providing for their families and taking care of their own personal health. Besides this dilemma, women who do indeed commence ARV treatment may find themselves faced with yet another problem that involves the appearance of their bodies.

2.4 Body Image, HIV and Gender

If a person is indeed able to overcome the many obstacles in receiving ARVs, there is the added problem of bodily changes that take place in people receiving HAART. ARVs are medications that improve the physical (and often the emotional) health of people living with HIV, but they are not without severe side-effects. In addition to side-

person as well as other social issues that might influence a person's adherence to the medication, which if missed can quickly result in drug resistance. However, the South African Antiretroviral Treatment Protocol (Provincial Administration Western Cape, 2004) sets this point at a CD4 count of < 200 cells/ μ l. This means that people who rely on free government programmes for treatment, must wait until their CD4 count is dangerously low as a normal CD4 count for adults is 1000 cells/ μ l (Wilson et al., 2004) whereas wealthy people with access to private healthcare schemes may be able to receive ARV therapy more tailored to suit their individual health needs.

effects common to other drug therapies such as nausea, dizziness and so fourth, there are quite visible effects caused by ARVs. People who are ill as a result of HIV often lose weight because of AIDS-related wasting syndrome (Wilson et al., 2004). Once some people are on ARVs they notice their thinness is replaced by a body shape change referred to as lipodystrophy (Persson, 2005), a condition in which fat is gained and is redistributed to a person's midsection and upper back and in which their face remains thin—almost gaunt. This side-effect can be long term and it renders a person's HIV status visible which can be detrimental in addition to the psychological effects of a fast and dramatic body shape change. Many studies on the psychological effects of body shape change have been conducted with HIV positive gay men in the West. These studies have shown that there are negative psychological consequences in that men feel unattractive or that their HIV status has been disclosed and they are stigmatised as a result of the body shape changes (Persson, 2005; Sharma et al., 2007). These body shape changes are also especially difficult for women in many cultures because of the demand that femininity requires the adherence to a particular body type in order to be seen as attractive and normal. Furthermore, these kinds of body image issues are not consistent across different cultures but in all cultures there are requirements about women's appearance and the ideal images are inconsistent with women living with HIV or women on ARVs.

There are very few studies conducted on HIV/ARV and body image in women and of those that have been done, their conclusions are somewhat problematic. In a study done in the United States, for example, Sharma et al. (2007) concluded that women living with HIV had body image issues related to their obesity and that weight loss programs are warranted for women living with HIV. These conclusions are problematic firstly

because the body image and beauty standards of women in the global South are greatly under researched. It is difficult to determine what body shapes for women in southern Africa pose problems and which do not, because standards and ideals that may be valued in the West are quite possibly different from those valued in the South. In addition, the Sharma et al. (2007) study does not address the social constraints placed on Western women in terms of the 'largeness' of their bodies. Another study regarding the relationship between lipodystrophy and adherence by Collins et al. (2006) finds that there is no relationship between the two, however there were very few women compared to men in the study. Finally, Reynolds, Neidig, Wu, Gifford and Holmes (2006) found that body shape change is distressful for people living with HIV. They however also failed to take into account how gender shapes and exacerbates this distress. Because women's bodies are under constant scrutiny whether they are ill or not, and because 'AIDS' is constructed as a disease that signifies the end of being 'beautiful' for women (Harrington, 1997), this has to be taken into account in the assessment of how women living with HIV experience and see their bodies.

Clearly compliance with the ARV regimen is a challenge for many reasons and the consequences are dire. The nature of ARV drugs are such that by missing one or two doses, the virus will likely become resistant and a person can compromise their physical health and ultimately their life (Wilson et al., 2004). It is also important to bear in mind the nature of the virus that these ARV drugs are attempting to combat. HIV causes severely impaired immunity. It is of great import for people living with HIV to facilitate the immunity that they still have. They must be careful to avoid situations that might promote infection by other microbes or stress induced illnesses as well as re-infection

with other strains of the ever-mutating HI virus. ARV drug treatment requires strict adherence to a rigorous drug regimen.

In administering ARVs, therefore, careful attention must be paid to social context and psychological states in order to determine the ways in which the demands of the drug regimens are being supported or compromised. Women who are suffering from the psychological after-effects of violence or abuse or who are continuing to experience abuse or stigma in their community are not in a good position to adhere to this strict schedule of medication. In addition, abusive treatment may compromise their physical health in ways that detract from the efficacy of the treatments. Both women receiving ARVs and those not receiving the medication must receive comprehensive support to help them cope with previous or ongoing violence, stigma, economic problems, and to ultimately empower and facilitate them with the resources to move from a dangerous situation so that they might lead as healthy a lifestyle as possible.

2.5 Gender, HIV and Gender-Based Violence

Gender-based violence and sexual power issues are increasingly being recognised as reasons for the rising incidence of HIV infection in women around the globe (Dunkle et al., 2004). Kistner (2003) points that women in South Africa between the ages of 15 and 29 have the highest prevalence of HIV. This same demographic has the highest incidence of abuse by a partner. Kim (2002) describes these findings as, “extremely significant because they indicate that young women, the demographic group which is already at higher risk of HIV infection in South Africa, simultaneously represent precisely the group which is at highest risk of rape” (p. 9).

The link between HIV and gender-based violence has only recently been identified in the literature. Until recently in the international literature, there was only the allusion to this link. For example, research conducted in Brazil found that women who were survivors of gender-based violence were less likely to use condoms because of gender inequalities that decreased their autonomy (Chacham, Maia, Greco, Silva & Greco, 2007). Other studies conducted in South Africa like the ones by Kalichman and Simbayi (2004) and Dunkle et al. (2004) acknowledge this link but point out that it is under-researched.

Gender-based violence is defined in Kistner's (2003) literature review for the South African Department of Health as, "violence directed against a person on the basis of his or her gender identity..." (p. 12). This type of violence has been described as, "one of the most obvious ways to convey the power difference between women and men..." (Kurz, 2001, p. 205). Most people think of gender-based violence as limited to rape or the ambiguous legal term, 'sexual assault.' Violence against women, however, takes many forms. Kistner (2003, p. 28) lists the following examples of gender-based violence: rape; battery; sexual abuse of girls; female genital mutilation; dowry-related violence; domestic violence including marital rape; intimate femicide; non-spousal violence; violence related to exploitation; sexual harassment or intimidation at work or school; trafficking women and girls or forced prostitution; violence perpetrated by the state; secondary victimisation/humiliation at the hands of police or healthcare workers; and economic violence including the withholding of money. Gender-based violence and the potential fear thereof have a marked impact on many aspects of women's lives.

Gender-based violence is often not reported, and therefore, most scholars believe that the small proportion of acts that are reported represent much larger real numbers. The fact that the National Woman Abuse Action Project (1991) (Kurz, 2001) reports that battering is the most common cause of injury to women (in the United States) illustrates just how large that number may actually be.

Novello (1992) reports that a significant proportion of women who are battered are seriously injured and seek medical attention. Gender-based violence not only creates great costs to the individuals who are battered, it is also costly for society as a whole. One particular result of violence against women that winds up being especially expensive to both the woman survivor as well as society is HIV infection. According to Raj, Silverman and Amaro (2004), men who abuse women are more likely to engage in behaviours that put them at a greater risk for HIV infection. These same men end up infecting their female partners, many times, through an act of overt or covert violence.

There are several ways in which the literature describes women's vulnerability to gender-based violence and a possible subsequent HIV infection: 1) Some women are raped and as a result of the actual physical trauma, they are more vulnerable to HIV infection (Kistner, 2002); 2) violence or threats might inhibit a woman's ability to negotiate condom use within an intimate heterosexual relationship (Guedes, 2004); 3) sexual abuse in childhood could lead to riskier behaviours in adulthood (Kistner, 2002); 4) disclosure of HIV status to a partner may result in violence (Rothenberg, 1995; Seidel & Ntuli, 1996; Temmerman, 1995; Van der Straten et al., 1995); and 5) it is also evident that women who are abused find themselves in desperate situations forcing them into sex work to support themselves (Dunkle et al., 2004) or causing them to resort to illegal drug

use (often needle drugs) to numb themselves, exposing them to HIV. In addition, these activities expose women to other health problems (like STIs) that can lead to HIV infection or exacerbation of illnesses if they are already infected (Kalichman & Simbayi, 2004). Thus the research shows that indeed there may be a strong link between women's experiences of gender-based violence and potential HIV infection.

Violence may also prevent women from obtaining treatment once they have become infected. Although there is little literature on the impact of violent events on women who are enrolled in anti-retroviral (ARV) programmes, it is reasonable to assume that there is some sort of impact on adherence to these medications. This assumption is strengthened by the fact that a positive HIV test result is reason enough to cause Post Traumatic Stress Disorder (PTSD) which has been shown to negatively affect adherence to ARVs (Brief et al., 2004) as well as impact the functioning of a person's already-jeopardised immune system (Delahanty, Bogart & Figler, 2004). For reasons of gender and subsequent poverty women face, it could be argued that women living with HIV require more or different types of psycho-social support for optimum adherence to ARVs than what they are currently receiving. This is where a wide gap in the literature and in the actual real outcomes can be found in that, although gender-based violence has been linked to HIV infection for women, there has been no reduction of either of the problems and the number of infections continues to grow for women despite continued efforts to educate people on HIV.

The literature shows that gender is closely linked to HIV. Some aspects of these links have been studied carefully such as stigma and care work. Less well studied are issues of women's body image and gender-based violence. In much of the research, these

concerns are not examined from the point of view of the women, who are central to the experience, who are HIV positive. This study explores all of these issues with a focus on the women who are living with HIV. How do they describe their experience with HIV and stigma, body image, care work, and violence? How might their experiences contribute to the gaps in the research and assist us in understanding the gendered dynamics of HIV?

University of Cape Town

CHAPTER 3: METHODOLOGY

3.1 Research Design

“Qualitative research is naturalistic, holistic and inductive” (Terre Blanche & Durrheim, 1999, p. 43). An inductive qualitative approach is required if the purpose of research is to study phenomena that are interrelated as they unfurl in real world situations (Terre Blanche & Durrheim, 1999). In light of the body of literature surrounding gender and HIV, the issues surrounding the lives, experiences, medical, psychological, or social problems of women who are living with HIV are sensitive, complicated and interrelated, and are best studied using a qualitative approach. Much has been written about HIV from the perspectives of scholars and medical authorities; however there appears to be a gap in the HIV literature when it comes to hearing the voices of women who are living with the virus and their ways of defining themselves and interpreting their own lives.

Additionally, the research shows that HIV positive women’s experiences are complicated by a number of issues including medical and social constructions of the ‘disease’, interpersonal relationships as well as gendered dynamics. A qualitative approach is deemed suitable to gain a more holistic understanding of these complex experiences.

This study focuses on the experience of women and gender because the disproportionate rate at which women are being infected with HIV suggests that gender inequality is a critical issue to examine. Feminist theory frames the research methods of this study because feminism offers a way to understand the gendered experiences of women living with HIV and the differing and dynamic power relations that have an impact on the women’s lives (Boonzaier & Shefer, 2006).

Traditionally, psychological research is a field in which men and a masculine point of view have dominated. According to Boonzaier and Shefer (2006), psychological research has been, “largely carried out by men, on men and for men’s benefit” (p. 8). Feminist research seeks to address this imbalance and can be characterised by several principles. Feminist researchers strive to: 1) Bring the voices of marginalised people back into the theory (DeVault, 1996; Boonzaier & Shefer, 2006); 2) conduct research that has political implications that may lead to positive change (Boonzaier & Shefer, 2006) and; 3) pay close attention to and attempt to minimise power imbalances between themselves and the people participating in the research (Boonzaier & Shefer, 2006).

While all of these principles were part of this study, the most important feature affecting the methods used in this research is the notion of bringing back marginalised voices or replacing the “view from above” with the “view from below” (Mies, 1983). This practice allows us to study, understand, and amplify the voices of people who have historically been “ignored, censored or oppressed,” in this case, specifically coloured women who are HIV positive and living in impoverished conditions (DeVault, 1996).

In addition to using feminist methods to gather information, critical feminist theory is also drawn upon in the analysis of the data by demanding that we pay attention to gender and the oppression of women via dynamic, male-dominated power structures. Gender injustice is a force for shaping the experience of women living with HIV and ideas and behaviours associated with gender are, in turn, shaped by many social issues including HIV. Furthermore, gender injustice is embedded in the social context of the families, work, and communities of the women who are living with HIV. Feminism shaped both the ways this study was conducted and the interpretation of the data that

were collected. Furthermore, because feminist tenets are also concerned with the end result or the action of the research, feminist methods also contribute to aspects of the practical goals of the research (DeVault, 1999).

A feminist approach requires us to find effective applications for our work in order to uncover the ways that social change activists such as HIV support group facilitators and members and ARV programme facilitators can help to modify those power relationships thereby decreasing women's exposure to HIV. Our findings must be useful to women who wish to successfully participate in programmes that will allow them to maintain their own physical health, decrease the development of resistant strains of HIV, and preserve their human rights.

3.2 Feminist Research, Social Constructionism and Discourse

Feminist research is said to be more than a "research perspective" or way of understanding women's experiences, but it is a critique on the way research has been traditionally carried out (Flick, 2006, p. 76) and these ideas can be viewed as being situated within a constructionist paradigm. Constructionist researchers, "begin by noting that meanings are highly variable across contexts of human interaction..." (Durrheim & Wassenaar, 1999, p. 63). Constructionists assert that knowledge and language are constructed through processes of "social interchange" (Flick, 2006, p. 80), which means that when a researcher interprets data, she must not only take into account the context and "social world" in which the research takes place but also how this social world and context were and are constructed (Terre Blanche & Durrheim, 1999). In fact, the constructionist paradigm is defined by Terre Blanche and Durrheim (1999, p. 6) as, "[A

paradigm] which aims to show how versions of the social world are produced in discourse, and to demonstrate how these constructions of reality make certain actions possible and others unthinkable.” Because feminist theory and the constructionist paradigm deal with discourses that are constructed in the social world, it follows that discourses that emerge in qualitative research are the constructs to which researchers should be paying close attention. A social constructionist approach attends to language and the discourses located therein.

Discourse can be defined as, “broad patterns of talk—systems of statements—that are taken up in particular speeches and conversations, not the speeches or conversations themselves” (Terre Blanche & Durrheim, 1999, p. 156). Foucault argues that power and relationships between the powerful and the subordinate are disclosed in discourse. Discourses are, “system[s] of statements which cohere around common meanings and values. . . [that] are a product of social factors, of powers and practices, rather than an individual’s set of ideas” (Hollway, 1983, p. 231). In the case of HIV, discourse abounds in medical settings, the media, government, and education. The dominant discourses surrounding HIV have an impact not only on what the world believes about HIV, but also how the research on the virus proceeds. Most importantly, dominant discourses have direct and indirect effects on the very people living with the virus.

According to Wodak and Meyer (2001), dominant or hegemonic discourses can be thought of as the general knowledge a population has about one idea or another. This knowledge in the form of discourse is not however a benign set of ideas for the education of the public. Foucault (1978) explains that knowledge does not make the ‘knower’ smarter or more powerful. Instead, knowledge can be used as a tool by which powerful

people exert power and control over less powerful people by telling them what to know and why. Knowledge can be a way of seeing and understanding the world that powerful people 'feed' to the less powerful in order to keep them from demanding justice or from even seeing injustice. Discourse is a vehicle by which knowledge can be disseminated. Dominant discourses are the ideas that tend to support and reproduce the status quo, thereby helping to maintain existing power relations. However, "Dominant discourses appear 'natural' denying their own partiality and gaining their authority by appealing to common sense" (Gavey 1989, p. 464). Dominant discourse is 'hidden' from the casual observer and can appear inevitable making other ideas unthinkable.

But Foucault (1980) reminds us that dominant discourse is not the only form of discourse. Power is contested and resistance discourses are an aspect of struggles over power. Disclosing and understanding dominant discourse and its variations, as well as resistance discourse are essential, therefore, to understanding the experience and behaviours of people, powerful and subordinate, who are part of those discourses. In order to challenge relationships of power, we must first expose what mechanisms are maintaining them and which are challenging them.

3.3 Study Context and Participants

Fifteen in-depth qualitative interviews were conducted with women who are participants in a community support group in a suburb of Cape Town, South Africa. The support group is the only one of its kind in a neighbourhood that is home to thousands of people living in public housing. The community is low income and people reside in small homes and flats as well as shacks made of corrugated metal and wood. In addition many

people live on the street or in informal shelters. The HIV support group is open to men and women who test positive at any of the several clinics and day hospitals in the area in which the support group is situated. I became a volunteer at the support group, meeting with the women on a weekly basis, helping with projects such as preparing lunch and food parcels and providing workshops on HIV risks, prevention, and care.

Poor women of colour represent a large proportion of people living with HIV in South Africa and thus, this study chose to specifically focus on the experiences of these women. This is an especially important population because while their numbers are significant, their voices have often not been heard in psychological research, and in HIV research in particular. In addition, the women's participation in the support group indicates that they are actively concerned about HIV in their community and might therefore be more willing or interested in talking about their lives. I also believed that the women, having participated in many discussions in the support group about the topics in which I was interested, would be able to discuss these issues readily. Their participation in the support group also made the women more accessible. In addition, the women in the group had a chance to get to know me and we were able to establish positive relationships and in some cases, friendships.

The interviews were conducted with women attending a support group in a suburb of Cape Town, South Africa of varying ages and backgrounds. Individuals were eligible to participate if they were a part of this support group and spoke English. I restricted subjects to English-speaking because I speak only English and I did not want to bring in further ethical and analytical issues by using a translator. Although English is not the first

language of about half of the members of the organisation, only a small proportion (about 5%) were not bilingual.

The participants ranged in age from 34 to 50 years. The women had differing occupations and skills including various types of factory work, domestic work, security guard work and many of the women were seeking work but unemployed at the time of the interviews for various reasons including disability due to their HIV status. Sixty percent of the women were unemployed including two women who have disabilities related to HIV and are unable to work because of this (this percentage excludes one woman who was retired). All of the women were mothers and their children ranged in age from newborn babies to adults. Fifty three percent of the women had male partners including ex-husbands with whom they had reconciled; thirty three percent of the women were married and; and 13% of the women were single.

The majority of the members of the group were referred to the organisation when they requested support regarding their HIV positive status from the clinic or day hospital. Those medical facilities often recommend this particular support group to community members as it is the only option for most people who cannot afford transportation to other parts of Cape Town in order to attend other support groups. The goal of this particular group is to offer services to HIV positive community members for a limited amount of time. For a time, the group offers weekly support group meetings run by facilitators and volunteers including members cum volunteers and modest food parcels that are distributed on a monthly basis only to people who qualify for it.

3.4 Procedures and Method

The interviews with women in the support group dealt with issues of gender and the psychological/social problems that are encountered by women living with HIV (see Appendix A for interview questions). The interviews were organised into four broad sections with detailed follow-up questions used when needed: 1) background information; 2) issues related to stigma; 3) effects of emotional and psychological issues on their well-being; and 4) violence.

Because the interview questions asked participants about their experiences regarding HIV and also about their lives in general, this study used in-depth semi-structured qualitative interviews. Dilley (2004) states that, "Qualitative interviewing is a way of finding out what others feel and think about their worlds. Through qualitative interviews you can understand experiences and reconstruct events in which you did not participate" (p. 128). This makes qualitative interviews particularly appropriate for this study since the goal was to explore the issues from the point of view of the women who are living with HIV as opposed to studying women's experiences with HIV from a medical or biological perspective (that asks women to structure their responses in very specific ways, by using survey methods, for example).

In July of 2006, I was invited by a personal contact to a community meeting in the area of Cape Town where my research eventually took place. This initial meeting included a number of local HIV, TB, and poverty activists. These particular meetings take place monthly in a community centre in a neighbourhood close to the one in which the support group is located. At this meeting I introduced myself as a University of Cape Town graduate student interested in doing research with women living with HIV and

made the other attendees aware of my need for potential participants. I was met with an abundance of offers including leads for interviewees and invitations from several local women's empowerment organisations as well as invitations for greatly needed volunteers at a Cape Town TB hospital. I was also fortunate enough to be introduced to the head of the support group of which I was eventually to become a part.

After a short interview about my intentions and permission from the group members, the head facilitator of the group invited me to become a volunteer at the support group. I began attending weekly meetings and various other events including a soup kitchen run by the group, as a volunteer in August of 2006. At each meeting I made the announcement that I was looking for women who would like to share their stories with me in a confidential discussion and the group was made aware that the research was for my Master's degree at University of Cape Town. Over the months, some women approached me after the meetings and we made arrangements for interviews.

As the interviews took place, I used the device of snowball sampling which "identifies cases of interest from people who know people who know what cases are information rich" (Miles & Huberman, 1994, p. 28). This method is very often used when research topics are highly sensitive or stigmatised, such as in the case of studying HIV. I asked the participants to suggest other individuals that may be interested in participating in an interview and I also requested that if the interview was a positive experience, that they pass the word on to other women who may be feeling shy about doing an interview.

Before each interview, I described the general topics to be addressed during the interview and the purpose of the interviews as a part of my Master's thesis. The participants were also asked to sign an informed consent form that includes a thorough

description of the study and the rights of the participant (see Appendix B). The informed consent was discussed verbally as well before the signing. I also explained that the interviews were a way for women's voices to be heard and for important and helpful ideas to be taken into account in the future treatment of women living with HIV. In addition, after a discussion with one of the facilitators, it was agreed that the interviews could be a way for women to confidentially make suggestions about the improvement of the support group. I made the interviewees aware of this before and after each interview and most participants took advantage of this opportunity. The suggestions made were reported back to the facilitator with careful consideration for confidentiality and subsequently, group members returned to me confirming their approval of several changes made as a result of the confidential suggestions.

Interviews lasted between 1 and 2 hours and were conducted in the private counselling room in the backyard of one of the facilitator's home. The interviews were scheduled at the convenience of the participant and usually took place during a quiet time, for example after meetings or on weekends. Each interview followed an established set of open-ended questions (see Appendix A) and these questions were used as a guide rather than a formula for the interview. The follow-up questions were only asked if the participant did not cover a specific area of interest in response to the broad question. All interviews were audio taped and transcribed. Participants were not paid, but as mentioned earlier, in the interest of reciprocity for their time and invaluable information, participants were offered small favours including transport, food, clothing and shoes, assistance with employment searches and the opportunity to make confidential suggestions on ways to improve the support group. The procedures outlined above, in terms of sampling and data

collection, are not atypical for qualitative studies of this nature. Qualitative research also accords attention to a critical examination of the role of the researcher in the data collection process and throughout the research endeavour. In the following section, I highlight my positioning as the one responsible for initiating and carrying out this study.

3.5 Reflexivity

As Terre Blanche and Durrheim (1999) assert, “the analyst is also part of the text’s content, and has to account for his or her role relative to the text” (p. 167).

Researchers have an effect on the analysis as they are able to shape research by extracting certain sections of the text to highlight an area of interest. As well, the analyst, as much as they may try to be objective in their collection and reporting of the data, will inevitably have an effect on the process. Part of understanding the data collected in qualitative interviews is highlighting dominant discourses as they operate in society, but it is also equally important to acknowledge that the researcher-participant interaction can illicit particular kinds of discourse as well. In other words, research is not done in a vacuum—the participant and researcher are reacting to each other in many and changing ways. In fact, Naples (2003) advises that participants as well as researchers play a major role in, “shaping what we come to know about their lives and the communities in which they live and work” (p. 37).

A major factor affecting the reactions of the researcher and the participant is power. As a Feminist researcher, it is particularly important to be aware of and attempt to minimise any negative consequences of power imbalances in an interview due to differences between researcher and participant (Mies, 1983). According to Wolf (1996),

one must be cognizant of the impact of power differentials in three areas: 1) Power imbalances due to demographic differences; 2) power imbalances due to the nature of the methodologies regarding whether or not the research is a relatively equal exchange or exploitative; and 3) power exertion in reporting of the data.

In most cases it is not possible to control for the effects of demographic differences between researchers and research participants. The women I spoke to and work with in the support group live in impoverished conditions. Most of the women in the support group live in small homes without plumbing and electricity and they speak openly about their struggles to find food (even a loaf of bread) each day. This was and continues to be the most painful part of working with the support group for myself and for the members of the group because I am so privileged in comparison to the other women in the group because of my education and subsequent access to employment and decent housing, food, and transport. The participants were aware of this socio-economic imbalance and the only way I felt I could be non-exploitative was by offering what I have in attempts to balance the relations of power and to engage in reciprocal research practice.

The feminist commitment to not exploit research participants by going into a situation to collect data and giving nothing in return was one that was especially salient for me. I offered my services and resources in several ways. For example, I regularly brought pots of food to support group meetings and I dropped bags of clothes and shoes I collected from myself and my family members to several women's homes. I also made myself available to group members in need of transport and I regularly drove members to and from group meetings and on errands to the Social Services offices and the homes of

family members. I made announcements during meetings inviting members to call upon me to help them search for employment opportunities and creating curriculum vitae. I also made presentations to the group regarding several medical care aspects of living with HIV. Members also used my voice as a confidential conduit between themselves and the group facilitators enabling members to make suggestions about how to improve the group's services.

The latter activity was especially important because when I passed on the suggestions to facilitators, one facilitator was able to use the women's ideas I had documented in my research in conjunction with information gained in her classes at ATTIC (AIDS Training Information and Counseling Centre). ATTIC is the official training centre established by the South Africa National Department of Health for people working in the field of HIV, an important source of policy for the women in the support group. In this way the group was able to implement new ideas and services in the support group in response to the members' needs and suggestions.

While this collaboration among the women in the support group, the facilitators and myself was successful, differences between myself and the women were significant. Determining what those differences were and how they were significant, however, is no easy task. It is important to attempt to be aware of all forms of difference but reflexivity is not a simple or clear part of the research process. The problem lies in what Naples (2003) describes as the "Insider/Outsider Debate." Often there are no distinct lines drawn between researchers and participants and even then, the lines are ever-changing. In this study, I entered the support group, initially perceived as an outsider. The facilitators, volunteers and members only knew me based on my status as an international student at

the University of Cape Town. In the beginning, therefore, these outsider markers had facilitators on their toes emphasising issues of their “transparency as an NGO” and the need for members to be on time and attend all meetings as if I were investigating the organisation from a funder’s point of view. The group members themselves were quiet but friendly in a formal way during this time. Slowly, it became clear that I was attending the meetings as a way to do research but in addition, to get to know people in a community which is in close proximity and similar demographically to my own, and to offer what services I could provide as a volunteer and most importantly, to act as a conduit between members and facilitators and ultimately policy makers. So my status as an outsider evolved as I collected the interviews and as members of the group began to understand my goals and realised that my family members were also members of the same community and of similar communities close-by.

The most obvious “Insider/Outsider” issue was of course, HIV status. I noted that the facilitators were quick to emphasise that they were HIV negative and frequently pointed out to the members this difference between themselves. In some cases there was an air of judgment as if to say, “I am a facilitator because I made good decisions regarding HIV infection and now I am here to help all you poor people living with HIV.” In fact, at one meeting one of the facilitators said, “We all have choices and you all made a bad choice, but your bed is made and now you must lie in it” (field notes, April 2007).

This HIV positive-negative distinction by several of the facilitators seemed to have had an impact on the members in that they noticeably deferred to people who visited the group with a perceived negative status. I was one of these perceived HIV negative people. Although I truthfully answered the question of my status when asked, I did not

announce it. I made a point of regularly emphasising the fact that becoming infected with HIV was not the result of a ‘bad choice’ and that anyone is vulnerable to the virus at any time in their lives regardless of their current status. For this, I believe an insider status of sorts was granted to me by some members. It seemed as though participants felt as comfortable as could be possible discussing events leading up to their positive HIV tests, in that I too am a woman vulnerable to this same virus and that I was not going to blame them as having made ‘wrong choices.’ Besides minimising and identifying issues of being an insider or outsider (or both) in terms of nationality, relative socio-economic status, gender and HIV status, there is also the pertinent issue of race-ethnicity.

Race is a human categorisation system supposedly based on ‘biology’ or ‘genetics’ and physical appearance, however it has been found that there are no biological or genetic markers of race in humans (Lewontin, Rose & Kamin, 1984). Ethnicity can be defined as the culture, religion and nationality attributed to each particular ‘race’ (Root Aulette, 2007). Since race has no real biological categorical basis, it is understood that it is a social construct that was created as a way to strategically marginalise people and as, “a repertoire of coercive social practices driven by desires and fears, as a framework for class formation, or as an ideology for nation building and territorial expansion, to name but a few” (Winant, 1994, p. 43). Although race-ethnicity is a social construct it becomes very real in the case of the research done for my thesis.

I immigrated to South Africa from the United States, the country that invented race as a construct for the facilitation of the kidnapping of men, women, and children from the continent of Africa and to ship and then buy and sell human beings into the institution of chattel slavery in North and South America. This government under which I

lived for many years is also responsible for the relocation and slaughter of millions of Native Americans, for the brutal treatment and detainment of members of myriad immigrant groups over the years, and for the murder of citizens and pillaging of countries in the Middle East. 'My' country is still the major contributor of the perpetuation of racial oppression, violence, and segregation locally and on an international level, through globalisation. The women I interviewed are from post-apartheid South Africa, a country also riddled with and still suffering from racial injustices and atrocities. Suffice to say, race is an important element in the reflexive process for this piece of research in terms of my own experiences and the experiences of the women I interviewed, but it is by far not as simple as 'black or white.' Race is a visible construct and many of the characteristics I possess are 'white.' I am perceived by most people, at least in South Africa, as white. But, although race is not biological, it does go beyond the visual sense of the word. Race-ethnicity is also an identity. In the case of my own personal identity, I cannot say that I have the same racial-ethnic identity as the women I interviewed, nor can I say that my identity is 'white.' Although I am in some instances perceived as white--and this is evident in an instance in the support group in which a woman that I had previously interviewed asked me to phone a potential employer on her behalf because she needed a "white lady" to phone. It was clear to me that most of the women in the support group perceived me as white and therefore there was a race distinction between myself and the women I interviewed. Given the social context in which the interviews took place; this perception placed me in a position of relative power. I am used to this perception however; I define myself as a person who is racially and ethnically 'in-between' because of my familial heritage and also because of my experiences of growing up in various

black schools and communities, particularly in the South of the United States, and in my diverse experiences internationally. I have also been in situations in which the social context and the construct of race placed me in relatively powerless positions and I have of course countless times been in the surreal position of 'passing' into conversations with racist white people who make assumptions about my identity. In terms of how my 'race' is perceived in the support group and the impact of my in-betweenness, I feel I am hyper-aware of race and able to consciously interpret what the women who participated in the interviews were saying in terms of race and in terms of the historical (and present) context of a country with dramatic racial-ethnic injustices, not unlike my own country. I will extend this reflexive awareness of racialised, and other differences between myself and the participants to the analysis of the data as well.

3.6 Analysis of Qualitative Data

The data were analysed using an emergent intuitive, inductive strategy which means that I did not start with prefigured thematic categories but instead I extracted categories from the data (Marshall & Rossman, 2006). The reason for this was because of the broad nature of the interview questions. The questions were specifically designed so as not to evoke particular themes necessarily, but rather to allow the interviewees to express their own ideas about their lives. The analysis process began by transcribing and re-checking tapes of the interviews for accuracy. The transcriptions were edited for any identifying information that may have shown up during the interview such as names of people, neighbourhoods, streets, hospitals and clinics.

Next, the transcripts were analysed in the broader context of the participants' lives. Because of the nature of the research, more specifically the social construct of HIV/AIDS and the gendered nature of the psycho-social problems that women experience in general, a social constructionist approach guided my analysis of the data. A social constructionist approach enabled me to examine the discourses that emerged from women's talk about their experiences of living with HIV. Discourse analysis enables one to uncover how broader relationships of power might be embedded in subjective constructions of individuals' experiences.

The idea of discourse analysis as a tool for understanding text or transcripts is a Foucauldian one. Foucault (1978) claims that there is no one "truth" in a text and that discourses in a text, "are a product of social factors, of power and practices, rather than an individual's set of ideas" (Hollway, 1983, p. 231). In other words, what people say is influenced by the dominant discourse surrounding the subject. Foucault also explains what impact these kinds of influences have regarding power and control:

We must make allowance for the complex and unstable process whereby discourse can be both an instrument and an effect of power... Discourse transmits and produces power; it reinforces it, but also undermines and exposes it, renders it fragile and makes it possible to thwart it...(p. 101).

However, Foucault's (1978) idea of "thwarting" dominant discourse, also tells us it is necessary to analyse texts for evidence of the rejection of dominant discourses.

Gavey (1989) explains how people are not so vulnerable to the dominant discourses on a particular subject that they can only manage to merely parrot the dominant ideas:

Individuals are not passive, however. Rather they are active and have "choice" when positioning themselves in relation to various discourses. For example, women can identify with and conform to traditional discursive constructions of

femininity or they can resist, reject, and challenge them (to a greater or lesser extent) (p. 464).

One way women, who may or may not have consciously identified the dominant discourses surrounding a particular topic, resist or challenge is by creating discourses of their own. Naples (2003) emphasises that, “discourse is not the property of individual actors or social movement organisations...” (p. 106). It is in fact possible for women to create their own counter discourses in response to or in addition to the dominant ones and this is a necessary thing as these counter discourses have material consequences in the possible furthering the agenda of the women themselves (Naples, 2003).

In this study, discourse analysis was deemed as the best way to tap into the ways in which the women speak about their experience with HIV. A discourse analysis was carried out using a style of discourse analysis procedures developed by Parker (2004) that stems from Foucauldian Discourse Analysis. I began by identifying ‘objects’ in each transcript. Parker (2004) asserts that these objects are marked as nouns and argues that identifying every noun used in a transcript allows the researcher to, “treat the text itself as the object of the study rather than what it seems to ‘refer’ to” (Flick, 2006, p. 326).

After the identification of the nouns, I extracted the ‘subjects’ from the itemised list of nouns. Subjects can be explained as people or characters in the transcripts that play a role in the ‘story’ that is the transcript. Next, I added explanations of the characters by identifying the ‘rights and responsibilities’ of each character as they were explained in the interview. Finally, I mapped the relationships between the characters and the interviewee and analysed these relationships in terms of ideology, power and institutions (Parker, 2004). This process was applied to all the transcripts allowing distinct discourses

to emerge within each individual transcript. And when the process was complete, it was evident that the same discourses were interwoven throughout and between the transcripts and encompassed by larger discourses of femininity and normalcy.

Four dominant discourses emerged in my analysis of the interview transcripts: 1) Being normal through work and men; 2) disclosure for better or worse; 3) taking care of men and children versus abuse; and 4) a women's body. The four discourses identified illustrate how women draw upon discourses of femininity and normalcy as ways of reconstructing themselves as humans in the face of dominant discourses that identify HIV positive women as something less than human. These discourses are discussed and illustrated in depth in the following chapter of this thesis.

3.7 Ethical Considerations

Given that this research is of a sensitive nature, I took great care in ensuring I did not harm the participants physically or emotionally. I also made sure to protect the participants' confidentiality at every stage of the research.

Because women living with HIV are considered a vulnerable population, I took extra care in terms of the ethical considerations in this research. I only conducted interviews with people over the age of 18, South African citizens and those who were mentally competent. In addition to these precautions, I only asked questions that were appropriate and directly related to my research. Since the subject of HIV and the issues surrounding it can be stressful I was especially careful to terminate any interview where the participant became too emotional or upset. There were several instances in which an interviewee began to cry. At that point I turned off the tape recorder and took a break.

During these breaks I explained to the participant that the interview should not cause pain and that stopping early was not a problem and it was in fact their right. In each instance, the participant insisted that the interview should continue as it was one of the only times they had the opportunity to share personal information regarding HIV and their lives with the guarantee of complete anonymity. In fact, after several interviews, the women expressed that a weight had been lifted and that the interview gave them a perspective on their lives that they had not considered before. In addition, the participants emphasised their need to express their experiences in order to ultimately improve the treatment of other women who have been more recently diagnosed and going through what they already have.

According to Scanlon (1993), researchers often unfairly benefit more from the research they conduct than do the participants of the research who actually provide the valuable information. To protect against this injustice, I have continued to volunteer at the support group beyond the time it took to collect the interviews. My current volunteer duties include driving disabled members to and from group meetings, putting together food parcels, serving food at the soup kitchen, presenting health and psychological information to the group during meetings, constructing curriculum vitae for members seeking work, and listening to and offering advice to members on an individual basis.

In addition, as a reflection of my commitment to feminist methodology, I have offered the findings of the research to the facilitators of the organisation so that they might be useful for creating positive social change. According to Reinharz (1992), one of the principles of feminist research is to use the research to influence social action in the ultimate attempt to change the status quo. This principle was followed in that the

facilitators, members and other volunteers from the support group have decided to implement the suggestions the women made in the interview for ways to improve the support group. In addition, one of the facilitators is planning to share the findings of the research with other support groups and activists.

All of the interviews were tape-recorded and each tape was destroyed after its transcription. The transcripts are kept in a secure location, to which only I have access. I did not reveal any of the participants' names at any time during the transcription and reporting process and the only identifying factor I use in this paper is that the participants reside in a suburb of Cape Town. The participants were fully informed of how the data I collected will be used and that there is a possibility that I may use a direct quote from their interviews in my thesis. Please see the attached informed consent form in Appendix B for additional information on the protection of the participants.

In the following chapter, the discourses that emerged from the transcripts of the interviews with women are explored in detail.

CHAPTER 4: ANALYSIS AND DISCUSSION

Discourse Analysis is a method of analysis that allows the researcher to be aware of the context in which the people being interviewed live and speak (Terre Blanche & Durrheim, 1999). In particular, critical discourse analysis pays attention to the power structures that ultimately influence the lives of the people interviewed as well as the ways in which they speak about their lives (Wodak & Meyer, 2001). The discourses identified in this piece of research emerge from the ‘talk’ that took place between the researcher and the participants. Talk as in the talk that takes place in an interview can be taken at face value. For example, one reason I choose to interview women living with HIV is that it is my belief that their voices are not heard and their opinions and needs are often not reflected in policy that governs how they are treated and dealt with in society (Bell, 2005). However, during the analysis of the transcripts and through numerous conversations with these women, it became apparent that there were important messages lying beneath the surface of our conversations. This reading between the lines is where discourse analysis becomes necessary. The overarching theme emergent in the interviews is that of women striving to be what they believe, or what they think I or others hearing them speak believe, is ‘normal.’ For these women, the struggle to be or seem normal was accomplished (or not) through exaggerated femininity. Women draw on hegemonic gender expectations in their four main discourses of work and relationships with men, disclosure, doing care work for men and children in the face of abuse, and the appearance of their bodies.

4.1 Being Normal Through Men and Women

Stigmatisation may be the single most problematic force in the lives of people living with HIV (UNAIDS, 2000). As the literature shows, this force may be multiplied for women living with the virus who have to make their way through the challenges of particularly gendered forms of HIV stigmatisation. Because ‘othering’ and gendered HIV stigma are done *to* women as well felt *by* the women against whom they are directed, naturally there are ways in which women react, adapt, and attempt to protect themselves against the forces of stigma. Gendered HIV stigma may be internalised or it may manifest itself in more concrete ways preventing women from working, going to school, feeling as though they are a valued member of society, and realising their full potential as human beings. In any case, women find ways of shielding or ‘disguising’ themselves from the full force of gendered HIV stigma and othering that takes place in their lives. The discourses about men and work emerge in the interviews as normalising forces against stigma.

4.1.1 Working is ‘Normal’

The importance of work for the women I interviewed is illustrated in the following interview excerpts. First we look at a section of Priscilla’s⁴ interview when she describes her feelings about being forced to disclose her HIV status publicly. She tells the story of being asked by the facilitator of her HIV support group to sit alone with her baby daughter at a table in a local supermarket and collect money for the organisation. Above the table was a banner with the name of the support group and “Support People Living With HIV/AIDS” painted in bold letters:

⁴ All names and places and other information in the interview transcripts that could be used as identifying factors have been changed to protect the anonymity of the participants.

Now I was sitting there and the people is looking at me and looking at my baby, you know? I can see they feel ashamed for me. And umm, “What’s your name? ...⁵ Are you HIV?” the people come and ask me. “Is this baby also HIV? ... Is this *your* baby, because it’s a very beautiful baby? ... Are you looking after this baby? ... Is this infant HIV?”

Although this situation may have been uncomfortable and a potential source of stigma or othering for Priscilla because the sign announcing her status draws a line between herself and the ‘normal’ customers at the supermarket, as the days went by she claims to have become more comfortable because of the clothing and monetary donations she was receiving specifically for herself and her daughter. In addition and possibly most importantly, she emphasises how much she looked forward to this activity because it was work:

And I really miss that shop. I really miss that supervisor. Especially two or three ladies who’s also working on the tills. But I was feeling better. And every night then they come and pick me up and I have something new that the people bought my baby, you know in the shop. I was really enjoying myself and you know, Anna, when they come in the morning—⁶come and pick me up, then I was ... I was so glad, “Oh I’m going to work.” I didn’t put in my mind that I’m going to sit there the whole day feeling shy.

Priscilla underscores how important it is to her that she has a way to provide for her child in ways that were previously unavailable for her because of limited job opportunities. In addition to the modest financial benefit, she seems to be eager to be involved in a work activity that could possibly allow her to feel like there is a purpose in her life.

⁵ Ellipses (...) indicates a pause in interviewee’s speech.

⁶ Hyphens indicate a sudden break in speech.

She may be telling me, and the rest of the world, that she is a worthy person because she can work, she can make money, and that she deserves to be seen as a valuable human being. It appears that Priscilla does not call upon her humanity to make this case to herself or others. She seems to be calling upon her ability to work and her success at working to earn some material things as an indication of her human value to herself, her child and to everyone around her. Priscilla's description of her feelings is ironic because she explains that it makes her feel good and it brings her happiness to be able to work. But on the other hand, she is expressing the point of view of the power structure that sees little value in her or her child, except if she can be 'productive' and earn her keep.

Linda also speaks about work in response to follow-up interview questions about the time when she first learned about her HIV status. She is employed as a domestic worker by a wealthy family consisting of a wife, husband and young son, for whom Linda cares during the day. Her employers have known about her status from the beginning, for the wife was with her in the doctor's office when her positive HIV test result was revealed. At one point after Linda's diagnosis and commencement of her ARV treatment, her employers asked her if she needed to quit her job and go back to another large South African city where her family resides:

I was so ... I did really cry very hard. Because they asked me now that I'm sick—now that I'm HIV ... blah, blah, blah ... I was already taking ARVs so what must I do? Or maybe I want to go back home and stay at home not working ... I just panicked. I said which means they are chasing me away. I just cried.

The thought of not working causes Linda psychological distress as she describes how "not working" causes panic in the excerpt above. Although Linda says she is now in

a good position in her life regarding her job stability and in the interview she is actually able to laugh at how worried she was at the time, she does go on to explain her fear of leaving or being fired from her job:

Linda: You know what, if I go back home ... I think I'm gonna die quickly (laughing).

Anna: Oh no!!

Linda: Yes (laughing)! Because, you know, your children knows that you are working. Ok, you come back home, now my children know I'm sick and you scared to tell your children what sickness do you have. And also then if they don't understand—when they look at you they will think that any time you gonna die.

Linda is expressing the notion of 'work or death.' She seems to be implying that being unemployed is like dying not to mention the issue of having to explain one's unemployment to worrying children. Once again, the relationship between her humanity and her ability to work seem to be contradictory. She says that continuing to work signifies to herself that she is not that ill. When she says that leaving her job may cause her to, "die quickly," she may be implying that without work, she would not be a productive, contributing, and *living* member of the community. But it also expresses the power relationship that places her in the position of having to 'earn her keep' or die.

The following excerpt from Elaine's interview illustrates this same contradiction. Elaine reiterates how important it is to her that her work abilities in a large factory be recognised despite problems that may arise because of her illness:

I told the people at work also ... I said to them, I don't want pity. I don't want people to pity me. I just want people to be with me as they are—as I am ... they used to be with me—just be with me as you are—as you used to be. Don't pity me. Because why, when you pity me, then I'm gonna think, Oh! The people is pitying me. And then they told me at work, "You must work like any other person

... like any other person ... you must work like any other person. And we gonna treat you like any other person. We not gonna treat you like you are a sick person.”

Elaine repeatedly indicates that she wants to, “work like any other person,” despite her HIV status. Her words here suggest that working signifies being ‘normal.’

As the above excerpts illustrate, work surfaces in our conversations in many forms. Sometimes work is mentioned as a problem that causes a women psychological stress. Sometimes work is described as an indication of normalcy and how a woman is or wishes to be a ‘regular working person’ despite the virus in her body. Work also emerges as part of the discussion of the economic challenges a woman faces. In whatever form the discussion of work takes place, it can be traced back to complex power and socio-political factors.

The history of work in the context of post-apartheid South Africa is complex and layered with different meanings for different people. Apartheid, a political and judicial system constructed by the white South African government, was based on the imposed physical and social separation of people based on their constructed racial classification (Salo, 2005). The Population Registration Act of 1950 forced South Africans into one of the prescribed race categories and the Group Areas Act of 1950 required people of colour to live in particular areas. In fact, people of colour were forcibly removed from their original neighbourhoods and homes, while white South Africans were given the best land and properties once belonging to the people who were forced to leave. Pass Laws were enacted in these areas of displacement and residents were required to carry and produce on demand, identity documents (much like “tags,” “passes,” and “free papers” required by law for black people traveling in the United States during the 1700s and 1800s) stating

that they were allowed to move outside of the confines of the neighbourhood. All sorts of localised restrictions were in place however, legislation such as the Coloured Labour Preference policy, for example gave preference to coloured people as cheap sources of labour over Africans⁷ in the textile and farming industries in the Western Cape (Salo, 2005). In addition, the apartheid government would not grant child welfare grants and public housing to families other than nuclear families. Because of this, women were the ones who received preference for the allocation of housing and grants (Salo, 2005). These circumstances created an unusual situation for coloured women, and to a lesser extent, black women living in the Western Cape. Although coloured women were subject to restrictions and oppression under patriarchy, at the same time they had an advantage over coloured men in the labour market. When it came to working, women were often the primary bread-winners (Boonzaier, 2001).

In addition to the specific historical context of apartheid, work is also a reflection of a person's worth in most nations in the world. Capitalist power structures do not place value on humans or grant them rights as a result of their humanity. Humans are only valued in terms of how much work they can do in a given amount of time. Consequently, work is what most of us spend the most time doing and many people define themselves according to their ability to do a job. On one hand, this issue of defining one's self

⁷ The terms "coloured" and "African" are two of many racial categories and sub-categories constructed by the apartheid government in South Africa. Although the categories are essentially arbitrary, they are still used in South Africa today. Coloured refers to people who are descendants of a mixture of 'races' and who often speak primarily Afrikaans and English. African refers to people who are 'black' and who speak primarily one of the following languages plus English: isiNdebele, isiXosha, isiZulu, Sepedi, Sesotho, Setswana, siSwati, Tshivenda, or Xitsonga. Some scholars use the term black to refer to all groups of people oppressed under the apartheid regime. In this thesis I used the terms "coloured" and "black" (instead of African) because these are the words that the women I interviewed use to refer to themselves.

through one's ability to do work can be dehumanising in that we are primarily a measure of our ability to enrich our employers. In contrast, work is important and potentially a joyful part of being a human. In a United Kingdom study done with women from 11 African countries living with HIV, Doyle and Anderson (2006) found that women expressed their desire to do work as a way to put their lives back together and to contribute to society. Women also expressed the notion that working gives them freedom and greater control over their lives. On a psychological note, in their study on discourses of gender and HIV in KwaZulu-Natal, South Africa, Hoosen and Collins (2004) point to psychodynamic theory as an explanation for why people are silent about HIV. Hoosen and Collins (2004) theorise that the people in their study may have repressed threatening or traumatic thoughts about HIV as those thoughts hinder their psychological functioning. It is possible that the women I interviewed also choose to talk about work because talking about work is easier than talking about one's positive status. In addition, although classical psychological theory has often been criticised as being inherently sexist and racist, it is interesting to note that Adler's individual psychological theory focuses on the idea that people's lives are a constant struggle for achievement and adaptation to life's challenges (Weitin, 2001). Taken into the context of the women in the present study, it could be said that the women are in a constant struggle to find material ways of surviving as well as sociological and psychological strategies to normalise themselves or move up the hierarchy from othered women of colour living with HIV in a patriarchal society.

While work may be seen by many as a defining characteristic of themselves and an activity that signifies a person as being normal, there are also other discourses that are related to the issue of appearing to be normal besides that of work. It seems that although

the women interviewed are seeking acknowledgment for being activists in the fight against HIV and also as survivors, paradoxically or maybe as an addition to their complex selves, they speak of the need to be viewed by others as normal people. This is a discourse that is related to ideas that have emerged in research about poverty and the health of women. The dominant discourse of poverty is that women who are poor have somehow gotten themselves into this situation because of poor choices and decisions they have made (Reid & Tom, 2006). In other words, poor women's health problems are their own faults. As a result of this dominant discourse, women who fall outside the norm of 'good decision makers' and who have become infected with the HI virus, are deemed abnormal. Talk of relationships and sex with men as a device for appearing to be normal despite harboring the abnormality of living with HIV is a pattern in many of the women's narratives.

4.1.2 Having a Man is Normal

Elvyra is married to a man who refuses to be tested for HIV but who also refuses to wear condoms. Elvyra speaks at length and at many times throughout the interview about his refusal to use condoms although she does not speak about this problem in a way that seems she is overly concerned. What seems to be her acceptance of his non-use of condoms may of course be discourse surrounding gender power structures and the sometimes impossibility of negotiating condom use for fear of stigma or violence as well as the fear that financial resources that a man is providing will be revoked (Hoosen & Collins, 2004; Petros, Airhihenbuwa, Simbayi, Ramlagan & Brown., 2006). However, Elvyra is the bread-winner in her household and the reason for the non-use of condoms may be due to a discourse surrounding her wish to have what she perceives as a normal

sexual relationship with her husband. In a discussion about her family's reaction to her status she moves from talking about her family's rejection to a new person who has entered her life:

And I've got this man in my life now. I ... we were married 30 years ago but he was in jail all the years⁸ So 2 years ago we met each other again and we got married last year. Next month we married a year—March we married a year So I went to go visit him in jail so he must have heard by my family that, "Elvyra is sick."

So I said to him, "Yeah I am sick" So he said, ok it's his choice and he don't want to lose me again. So we got married and we living together now. And so I said to him, "Anyway, I don't want you also to get sick because then we both is gonna get sick. We can't look after each other. Either you must use a condom..."

So he said, "No." he's not gonna use a condom ... he's not gonna use a condom. So we having unprotected sex.

Because it is not always easy to convey a mood in a typed transcript, an explanation about the way in which Elvyra made these statements is necessary. At this point in the interview, she speaks proudly of the marriage. It is important to note that she uses the words "*We* [emphasis added] are having unprotected sex." The words she uses implies that she would like to be seen as having been a part of the decision to not use condoms. In addition she appears to be proud of her married status and that she is having what she perceives as a normal sex life in her marriage, in other words, no condoms.

Also of note in this excerpt is Elvyra's choice to reunite with a man with whom she was married to and divorced from prior to the subsequent marriage in which she became infected with HIV. It is possible that the man she is now married to may represent her life as it once was, i.e. normal.

⁸ Four points (....) indicates omission between sentences.

Talk of not using condoms as part of being normal arises again when Rosalind, who is a volunteer peer counselor for couples who have recently tested positive for HIV, is speaking about what she tells her clients in counseling sessions:

And it's not the end of the world if you're positive. Yes I tell them. I tell the couple, "It's not the end of the world. If you want to use a condom, you can use a condom, but don't go to other partners. Sleep with each other. Stay with each other if you don't want to use a condom."

Rosalind is suggesting that monogamy negates the necessity to use condoms in couples who are HIV positive. Her advice to couples may be conveying her beliefs about what it means to be in a normal partnership or marriage.

Being normal as a function of having a relationship with a man is seen again when Elaine speaks about a confrontation with a woman who was rudely commenting on Elaine's thin body:

The other day, the other woman said to me, "Oh you so thin! Your boyfriend is too long—so tall!"... She said, "I'm 57 and I don't even have a boyfriend."

I said, "That's nothing to do with me. That's your problem. I can't help if I've got a boyfriend who can help look after me. And you don't have one. That's your problem."

"But you so thin and I'm so lekker fat⁹ and I ..."

I said, "That's nothing to do with me! That's nothing to do with me."

The conversation with this woman in the neighbourhood is significant because Elaine has been stigmatised and publicly humiliated by the people in her neighbourhood. She lives in public housing where many people reside in close proximity and in which there exists tight networks of friends and family which she says results in little privacy..

⁹ In attempts to maintain the accuracy of the women's statements, words in Afrikaans are left in block quotes. The English translation of "lekker fat" is "nice and fat."

She frequently mentions her boyfriend during the interview in such a way that suggests she is proud that he is part of her life and although he is not perfect, he brings a sense of normalcy to it. In addition, our discussion ends on a high note when she speaks of the possibility of a future marriage:

He said to me he wants ... I asked him, "Now why do you want to marry me?"

"No Elaine, I know we are together—we can stay together."

"And ok, I'm just waiting for that time to come. I'm not going to give you no ..." But I said to him, "If you want to get married, we must get married on your birthday." And I told him, you know what—the 27th! I was married also on the 27th that time. Now his birthday is also on the 27th of June. Now I said to him, "Imagine now I'm going to get married again on the 27th of June!"

He said to me, "No, but it's fine! It's on my birthday."

I said, "Yes, but that time I didn't know your name. I didn't know you. But now you—the 27th of June." But I don't know if we are gonna get married.

But he said to me, "I want to marry you, but you musn't tell anybody now at this moment. I want to make it a surprise. Don't even tell the children. I want to make it a surprise."

I said, "Ok."

Elaine excitedly describes her hopes of marriage and "getting married" repeatedly. Her hope of a marriage may be a passport of sorts back into the normal world. It seems that a positive HIV status can be perceived as having been turned around with a newly acquired status of "married."

The discourse of work emerges as a theme in the interviews because work is a way in which many people measure their worth. The women interviewed speak about work as it is a way to show society that they are valuable and normal women. In addition it seems as if women living with HIV need an added ingredient to boost them back up from 'being HIV' to 'being normal' and that ingredient is a man. The women interviewed also express a sense of normalcy in a life that is marginalised in many ways including

being HIV positive, in having a man partner or husband. Having a partner or husband is also a symbol of status as well as a cry out to society saying, “If this man values me, then so should you!”

Another possible reason for the necessity of a man partner to achieve acceptance and normality is related to the way in which marriage is constructed. Hoosen and Collins (2004) found that a discourse of marriage being constructed as monogamous and also as a place of safety from the vulnerability to HIV infection emerged in their data too. Along this same line, Castle (2004) states that HIV is a condition that is seen as having been imposed on persons who have “transgressed social norms” (p. 13) and have had sex before marriage (or outside of the safety net of marriage) and therefore deserve to be infected. Evidently for the women I interviewed, marriage or a marriage-like relationship with a man acts as a barrier against the blame and stigma against women living with HIV that takes place in society. As Lekas et al. (2006) conclude from their research on stigma, one way women cope with stigma is to emphasise something positive about themselves. In this study, the women choose to emphasise elements of their femininity. They draw on widespread discourses of ‘normalised femininity’ in order to emphasise positive aspects of their living with HIV.

Relationships with men may be seen by the women I interviewed as advantageous in that it makes them more normal and that there may be a possible financial advantage to having a ‘man in the house.’ However most of the women who participated in the present study are the bread-winners and the money often goes towards taking care of children and men. The question remains, how effective is it having a man to bring back normalcy?

4.2 Disclosure For Better or Worse

There are myriad ways and contexts in which the discourse of disclosure emerges from the interviews conducted for this thesis, but the three main ways are: 1) Disclosures at work and the favourable and unfavourable consequences of this; 2) fear of or reactions to disclosure by children and mothers; and 3) disclosures to relative strangers or coworkers as a way of seeking acknowledgement of being a survivor and activist and of following the advice of medical and psychological authorities even in the face of HIV stigma.

Although the prevalent disclosure discourse of the medical and HIV activist communities encourages women as well as men to reveal their status publicly, it may or may not always be an absolutely positive step to take as many of the women interviewed for this study have found.

Elaine has disclosed her status at work and at the weekly support group meetings and frequently talks about the problems that have resulted from disclosing. Throughout the interview she mentions problems with the management at the factory where she works. She also talks about work while she is describing the day of her positive HIV test. On this day she had to attend a mandatory meeting with several members of management regarding her repeated absences from work:

... the meeting was too heavy and they didn't want to listen to me so I took out the letter (HIV positive diagnosis from the clinic) and I was crying ... Then they said to me, "What's wrong with you Elaine?"

I said to them, "No, I just found out now that I'm HIV positive and I don't wanted to tell you."

They say, "WHAT? Is it really true?" I give them the letter ... They said to me, "How did you find out?"

I said, “No, I went to the clinic and the doctor asked me to do an HIV test so I did the test and my test came out I am HIV positive.”

And they said to me, “Ok Elaine we can’t fire you now. We don’t have to fire you.”

The fact that Elaine was forced to disclose her status, quite possibly a person’s most intimate secret, is an illustration of how all-powerful a workplace is for a person. Elaine was forced to choose between her privacy and her job. Fortunately for Elaine, this disclosure, although painful, may have become the ace up her sleeve giving her possible peace of mind in terms of job security. And this is no small security in a country, much less a world, in which job security is rare and in which jobs are a defining part of our selves. When management found out that she was HIV positive they were legally restrained from firing her even if they were disturbed by her absences¹⁰.

Nazreen also speaks about problems she has had at work regarding disclosure and stigmatisation because of her positive status. In this section of the interview she discusses a confrontation she had at a previous job with the boss of the small factory in which she was doing ironing work:

I go to my boss because I must tell her because the steam from this iron isn’t good for me, for this virus. So I go to her—lunch time when she was alone and I told her, “Umm listen here, I’m HIV.”

“SO!! What must I do?!” she told me.

So I said, “No, I’m just telling you that I’m HIV—isn’t there something else that you can give me because the steam is not good for me.”

So she said, “I think you must just take your bag as well. Because I don’t have time for you people. You must attend clinic or doctor every month. You

¹⁰ The South African Employment Equity Act requires employers adhere certain procedures in the dismissal of HIV positive employees (Department of Labour Employment Equity Act, 1998). Although this act and other so-called protective procedures in the South African Constitution leaves much to be desired for people living with HIV in that some of the regulations are voluntary on the part of the employer, at the same time the government has professed its commitment to people, women in particular, working and living with HIV.

must be in your work. Your work is your work.” That is what she told me. So I took my bag and I go, because I don’t need that.

Elaine and Nazreen’s stories illustrate how disclosure can have contradictory results. Disclosures can be perceived as a sign of weakness or vulnerability or can cause weakness or vulnerability. Some women, such as Elaine, however, may be able to turn this vulnerability upside down and make it into a source of power, but others, such as Nazreen may not be able to turn it on its head. Disclosures to family members can also go either way.

Although only one of the open-ended interview questions mentions the word “family”, the questions about disclosure elicited long discussions about the women’s struggles with their children and choosing to disclose or not disclose to them. They also express the need to disclose to their mothers and speak of some of the struggles they faced in doing so. Some of this talk of children and mothers may be a product of gender identity as the women may be feeling that speaking about their children and mothers was expected, but another part of the talk may also be due to the struggle they face in regard to the discourse of disclosure and being pressured to disclose to the people closest to them—their mothers and children.

Priscilla is often quite upset and sometimes cries during and after support group meetings. As a result, her counselors and support group facilitators have repeatedly encouraged her to disclose to her family members as they have identified non-disclosure as her primary source of anxiety:

Sister¹¹ Aisha, she told me I must disclose. She know it's not easy for me but umm she know she is not the one with the virus but I must just try to disclose and if I don't have the courage to disclose, then I must just contact her or Nazeem (Sister Aisha's husband and the facilitator of the support group) and they will do the talking and they will exactly tell my people, my family, whatever ... But Anna, I'm not ready yet.

I responded to Priscilla by asking why she is not yet ready to disclose and she explained what she believed would happen upon her disclosure:

I don't know if my mom is gonna accept me as her child. My mother's an alcoholic. I'm scared to tell my daughter. Really I'm very scared to tell her and my mother ... But I really want my mom, but I'm also scared because right now she is standing in the public, tell the people who I am and what I am. Priscilla describes her feelings about disclosure as being "scared."

Priscilla seems to be torn between feeling the pressure to disclose from the healthcare and activist communities and the media, and the anticipation of a stigmatising response from the people she discloses to as well as the community who may find out in time.

In response to a question about why she decided to get an HIV test, Elaine also begins speaking about disclosure, specifically to her children. She explains that once she decided to attend support group meetings and disclosed there, she began to disclose at home:

Then I made myself strong and go to [the support group] and I get there and it's 2 years that I'm now with Nazeem now. And I go there and I introduce myself cause they gave me the address and they told me I must go there. And I introduced myself to them and from that time on, I'm brave. I can talk ... even

¹¹ The term "sister" denotes "nursing sister" or "registered nurse".

afterwards I told my children I'm HIV positive and that I was ok, but I was crying. I couldn't tell them what's happening—what's wrong with me. Then I told my children but my one daughter she was so crying. The other one just said, "Ok. It's fine but we must all keep it confidential—we musn't tell other people." And then my one daughter she was crying and crying ...

Elaine speaks of the strength she gained in her support group disclosures and how this may have facilitated subsequent disclosures to her children. In fact, Elaine claims to feel that a great burden was lifted once that disclosure took place. In response to my question about what her greatest worry is since finding out she is living with HIV, she states:

I think I'm not anymore worried. I'm not anymore worried. Because the first thing that worried me was the children—how I'm gonna tell my children. Since I told them, I'm not worried anymore.

Denise also speaks about disclosing to her children. Denise explains to me that she does not intend to disclose to anyone in the near future. She anticipates a bad reaction from her family and community. She says she believes the worst reaction will come from her children who do not get along well with her:

Anna: When...you said that no other people know now...

Denise: No. Even my children doesn't know.

Anna: Why have you decided not to tell your family?

Denise: Because I'm still—HIV. You understand? If I got AIDS and all umm ... started to get my ARVs so I can tell them but I'm not gonna tell my children because they gonna tell the family—the family will tell them.

Anna: Why don't you want them to know?

Denise: Because they are rude. They stay with me and they are rude to me.

Anna: The children? Your own children are rude.

Denise: Yes.

Anna: What do you mean they're rude?

Denise: They don't respect me. They don't ...

Anna: If they found out ... if your family told your children, how ... what would they say to you—your children?

Denise: Umm...I don't know what they gonna say but the thing is I know they are rude. Like now you know, I've got problems but they are always want to talk about their things in the group (other members of the support group), but I can't. Because every time when I want to talk, my eyes ... they too full with tears so I can't ... [crying] ...

Anna: You feel sad when you talk about it.

Denise: So I don't talk about it. I will tell. I will make time to talk and so I can feel better ...

In the excerpt above, Denise expresses the great deal of pain that may be a result of her not receiving the support needed to stabilise her relationship with her daughter. At the end of this excerpt where she says she will “make time to talk and so I can feel better,” she may be drawing on the discourse that disclosure leads to peace of mind and she may be suggesting that her pain stems from her reluctance to disclose. Denise as well as several of the other women mentioned have mixed feelings about the safety and effects of disclosure in their family lives. They speak of knowing that disclosure is deemed necessary by authority figures but it seems that they have also analysed this discourse of disclosure and come to the conclusion that it may not always be the best choice. On the other hand, parts of the discourse of disclosure may be (or may be perceived as) valuable to a woman living with HIV because it relieves them from the stress of keeping it a secret. But this is also based on the assumption of the ‘talking cure,’ which is the foundation of the discipline of psychology and psychotherapy—a discourse of the dominant medical establishment.

Linda is the one person in the support group that has described herself as living a relatively stress-free life. She speaks of having come to terms with her status and having supportive employers. In addition Linda quickly planned and executed a successful

disclosure to her children and other children in her family. In this portion of the interview

Linda tells the story of when she disclosed to the children:

... And my sister's children because they're going together—they staying together. We just collected them. Then we sit down. It was Christmas Eve in the morning. Then they just sit on the floor. We closed the door, me and my sister. Then I asked them about what do they know about HIV. Each and every one saying anything that they know ... "Yeah, HIV people can die ..." Other said, "No, they can live longer ..." You know ... others say—they talking about a support group. We didn't know that they knew so much. I was so ... Then I told them,

"Ok if somebody in this family is HIV—HIV positive, how are you going to react?" So, the other ones said,

"That person, whoever he is, we must support him—show them that we love him. Because at school they teach us that and even your friend is HIV positive, he's still your friend. And we can't get infected by chatting, hugging, sharing food—all those things. So, there's nothing wrong with that ..." So I think okay. Even those ones they just said, "HIV person he just die—he going to die," I can see—I did see that ok they also now understand what is going on. Then I tell them ... [crying] they all stood up and hugged me!

Linda claims to have experienced a successful disclosure which so far has benefited her; however, she speaks of a problem as well. Linda goes on to speak about struggling with the decision of disclosing to her elderly mother. She explains the dilemma here:

... my mother doesn't know yet. She's old so when I think about her ... because in 2004 my brother passed away. We were three of us. It was my brother and me and Mary (Linda's sister). So my brother passed away so it was difficult for my mom. So, sometimes I think I can't tell her ... I ... maybe she will be devastated. Because you know elder people they believe in that it's better them to pass away and leave us behind because if we passed away, who's gonna bury them. They believe in that, you know. So, we discussed with my sister. My sister say, "Just keep it that way."

In addition, when Linda is asked about what things need to be improved or changed to better help women living with the virus she speaks of the need to educate families of women living with HIV:

It's a long way to go ... because even in the families—especially in the families So, you can be supported by other people but the important support is from the family. If the family doesn't support you, those people—they can't do anything. They can help you with things that they can help, but as a woman, if you got children, you see? We think that ooh ... if someday my days have come—what about my children? Because, the important person who can look after your children is your family. So, if the family, it's not supporting you, where are you going to leave the children? Where? It's ... it's difficult. So, if maybe people can get more knowledge—especially the family. Because other people like us like in the support group—we support each other. We don't care—we just love each other and we share what we have, but the families ... it's difficult. It's the most important support.

Interestingly Linda is suggesting that fear of disclosure to family is not because of a fear of stigma. It is a practical fear of losing support, in this case being able to call on family to help her with her children and arranging her life so that her children can survive when she is gone.

Linda agrees fundamentally with the tenets of the dominant disclosure discourse and, in addition, she points out a more practical benefit of disclosure for women in particular—the issue of who will help her with her children when she is sick or dying. However, again Linda sees some of her personal issues surrounding disclosure as an exception to the rule:

If the family maybe can be taught and understand. Except that like me—my mother ... I know maybe she can't understand, but my mother she's got ... she's eating the treatment of high blood pressure. Maybe she can understand, but back on her mind, sometimes she would think, "Oh! ... which means..." Because everyone knew this rumour without understanding that it's not like that.

Everyone knows that if someone's HIV positive, she's gonna die—and it's not like that! So, she will feel like, "Ok, I heard people do that ... now my child!" You see? They don't understand, especially elder people—they don't understand.

Elvyra's family reacted negatively to her disclosure over 15 years ago. Her mother insisted she use separate eating utensils and was concerned about her toothbrush being near the rest of the family toothbrushes. Only now has Elvyra's youngest sister approached her and asked Elvyra to forgive her for years of estrangement. Nevertheless, Elvyra emphasises the importance of disclosure to the family. She is also a volunteer peer counselor and she emphasises this in her sessions as well:

Elvyra: If you got a good counselor and your family's support—you get a family that supports you, then nothing will go wrong.

Anna: Do you think the counselors are good?

Elvyra: Some counselors are very good. They very good.

Anna: Is that person the most important support in the whole process?

Elvyra: Sometimes it is your family. If you got a family that supports you all the way, then you feel very good. If you've got no family that supports you in this, then you will have problems all the time.

Anna: What do you tell people if you were counseling and they said, "I can't tell my family," or "My family hates me now." What do you tell them?

Elvyra: I will tell them just fast and pray. Your family will come to you. Someday all the other—your family will come. Because now the other ... you know who's coming to visit me and phoning me now and then? My baby sister. So my friends said, "[gasp] Wow! What?" So no. So I said to my friend, "Just pray. Pray everyday and ask God just to forgive her for what she told the other people and she will come right one day."

It is apparent that disclosure is a complicated decision to make and many times it is simply too risky to disclose and the risk is not just one of stigmatisation. Nearly all of the women in the interviews identify social as well as material support—jobs, family support for children, a house to live in—as the risk in losing these material resources they

believe they are taking with disclosure. However it is interesting that some of the women I spoke with have enthusiastically disclosed to quite a few people who are relative strangers for example, coworkers or new people in the support group, if not complete strangers, because they are less afraid of hostility from strangers than the removal of material support by family members. A good example of this kind of random disclosure is seen in Elaine's interview. Elaine speaks about being on a roll in terms of disclosures. She tells the story of one of the many times she has disclosed her HIV status to a relative stranger:

Or if I'm drunk, I walk in the street I tell this person ... "Jy!¹², you know what, I'm HIV positive. Leave me alone." There was one guy—he's a church-goer. He talked to me about God. I said, "No I don't want to listen about God." I was lekker drunk that night. I went home. I said, "I'm HIV positive." He came to me the next day or the next week—came to ask me if I want to go with him to church. I said, "No I don't want to go with you to church."

He asked me, "Do you know what you told me yesterday?"

I said, "Yes I know what I told you! But don't come and pity me because I'm HIV positive."

In disclosing to strangers, Elaine may be fulfilling the need to disclose, as many people living with HIV are pressured to do. However, this type of disclosure might be safer than a disclosure to a family member because there is less to lose. Elaine spoke of another occasion in which she disclosed to a coworker she was not very close to:

Yes and that other lady at work also said to me I'm very strong. She said to me, "You very strong woman. Because why other people don't want to talk about their status. They don't want to tell nothing."

I said, "No, if you talk, then you can make yourself better." If you keep yourself in like Priscilla--Priscilla don't want to talk. That's why Priscilla is

¹² The English translation of the Afrikaans word "jy" is "you." In this case, Elaine means "Hey you!"

always crying and crying and crying because she don't want to talk. You must talk. If you talk, you talk the sickness away from you ... but if you sit and cry...

In this instance Elaine may have taken a greater risk in disclosing to a coworker, nevertheless, her colleague reacted positively to the disclosure. In the above excerpt, Elaine illustrates the belief that “talking” about one’s status, “can make you feel better.” And she cites Priscilla’s pain as a direct result of her reluctance to speak about her status. Contrary to Elaine’s belief, Priscilla *has* disclosed to relative strangers as well. She talks about the disclosures she has made to the teachers and principal at the school her children attend:

Priscilla: I go to my two boy’s school. I go tell the principal—I think they must know if anything ... maybe like two boys is at home for more than a month, then they must think, “But that boy’s mommy is sick.” So you see? I just go to the principal and to my eldest son, Ryan, and I go to his teacher.

Anna: How did they react?

Priscilla: The principal did call the two teachers to the office and so they prayed for me. Yes and umm that’s all. So, I go to my daughter’s high school, go see her teacher. So, the teacher come to the office and I told her about it, “Maybe if there’s anything that if Lize is more than a month out of school, then they must just think, “Maybe Lize’s mommy is sick.” But she said she will contact me—she will come and make a turn by there. That’s the only people that know—my partner and my eldest daughter’s teacher and my two boys and the principal and teachers.

Priscilla relates the practical reasons for these disclosures but these are not the only relative strangers she has disclosed to. Priscilla participates in public disclosures held at churches in various neighbourhoods in Cape Town. She told me about how good it feels and how much of a relief these church disclosures are. In addition Priscilla talks at length about her time collecting donations at a supermarket, where her status was made public with the sign above her table stating “Support People Living With HIV/AIDS:”

You know, so ... there was a part of me I didn't like the idea, but you know so time just go and come by so I just said, no if they come and ask me again, then I'm gonna be just honest. Because I don't know the place—I don't know the people. So, kids, children came to me ...

Here, Priscilla alludes to having empowered herself to disclose to strangers, but only because she is not from the area and does not know the people there. These sort of random or spur of the moment disclosures are interesting because Elaine and Priscilla as well as many other women living with the virus do not consider themselves as 'out' in regard to their status. For example, Elaine who has been able to disclose to complete strangers and distant coworkers also talks about her need for privacy in the matter:

There was another lady also, I think from work ... "I heard you got AIDS."

"Oh," I said, "Who told you so?"

"No I heard the people say you've got AIDS."

I said, "If I've got AIDS, it's got nothing to do with nobody." I said, "The people likes to talk a lot of things." That's why since I got this I haven't got friends anymore because all the friends that I had are gone. And if I told them I'm HIV positive, then the whole world will know that I'm HIV positive.

In the above excerpt, Elaine states that possibly because some people to whom she has disclosed have not kept the information confidential, she has lost friends. Because social support is so scarce, her loss of friends may have been a high price to pay for having disclosed as the dominant discourses say people should. Priscilla who also has also publicly disclosed has also expressed her frustration with not being able to disclose to those people she is closest to. Here she explains what happens each time she visits her doctor:

Because when I go to my doctor, it's every month just cry, cry, cry, cry. I don't know Every time when I sit home, I'm fine. But every time it's my check up for my doctor, then I just cry and cry ... He said it's great to cry. He said I must talk and if I want to cry, then I must cry—I will feel better. And it's true. When I cry, then I feel better. And when I'm talking and ... I feel better ... Then he asks me, "What is it, Priscilla? What's wrong?" Then I tell him,

"I still live with this secret in me for two whole years. I don't know how to disclose. I'm scared to disclose." So he told me,

"If you are scared, just leave it. Maybe you will tell your family or your parents or what-what ... just leave it." But every time, Anna, when I go and see the doctor, then just tears. I don't know why.

Priscilla explains here, how her doctor encourages her to talk and cry as a way to feel better. Ironically, she says, upon hearing her pain and frustration regarding disclosure, this same doctor says that if she is scared to disclose then, "just leave it." On one hand the dominant discourses pressure people to disclose, but in reality it is possible that even the members of the medical community see that disclosure is complicated and anxiety provoking and the risks may outweigh the benefits.

Even though stigma is a perceived and real barrier to disclosure, Priscilla and Elaine have been able to disclose in certain situations with mixed results. The contradiction is that they want to and do disclose to relative strangers but at the same time they claim to be unable to disclose to those closest to them because they physically need the people closest to them to stay close-by. Ironically, it is for this same reason the medical community believes people living with HIV should disclose to their families (because their families are their main source of practical support), which is the same reason it is such a risk for the women to take in the case that it fails. If their families or employers reject them they are abandoned without the material support necessary to survive.

Discourses of disclosure are important as they relate to HIV and medical treatment and psycho-social support (Klitzman et al., 2004). Practically speaking, disclosure is necessary for people who are living with the virus and wish to obtain government and community resources (Castle, 2004), and specifically the commencement of ARV treatment. In fact, the Antiretroviral Treatment Protocol for the Western Cape (Provincial Administration Western Cape, 2004) requires a person disclose to “at least one friend or family member or have joined a support group” (p. 4). The premise of this policy rests on the notion in the medical community in South Africa and in many other parts of the world that disclosure facilitates psycho-social support which has a buffering effect against HIV stigma (Friedland et al., 1996). The medical community also asserts that disclosure, to partners in particular, offers a psychological release which is beneficial to psychological health (Derlega, Winstead, Greene, Serovich & Elwood, 2002). This notion of disclosure as a type of catharsis is also reflected in the data in the present study as well as in Squire’s (2007) research involving HIV positive people in South Africa.

In addition to the material as well as social support that may be gained upon disclosure, the South African media and activist communities like CADRE (Centre for AIDS Research and Evaluation), the TAC (Treatment Action Campaign) and the HSRC (Human Science Research Council) have created and propagated a counter-discourse calling for social change in the realm of HIV stigma. It is the agenda of these agencies to advocate HIV disclosure as a way of restructuring society such that stigma is an impossibility. It is many activists’ view that by inducing a sort of mass-disclosure of all persons living with the virus, HIV stigma could be abolished.

Many of the women interviewed in this study, have such a strong anticipation of stigma and rejection that they cannot bring themselves to disclose. This fear to disclose in South Africa in particular may have to do with discourses of fear set forth by the media in their over-reporting of events involving HIV-related violence and discrimination (Squire, 2007). However stigma is layered and multi-dimensional (Fife & Wright, 2000) and the fear of stigma upon disclosure may be due to numerous factors. One factor of note in this study is the commonly voiced problem of not knowing *how* to disclose. The women in the support group involved in the present study shared their fears in support group meetings. They explained that a great part of their fear comes with not knowing how to set up a disclosure and not knowing how to tell beforehand, if the friend or family member will react negatively. This idea also encapsulates the struggle the women I interviewed have with disclosing to their mothers and children in particular. The medical and activist establishment may be right in their advocacy of disclosure but within their messages is the assumption that orchestrating successful disclosures is a skill that most people inherently have, which it most certainly is not. In addition their messages fail to take into account that each disclosure has its own unique set of circumstances including barriers and fears that women in particular, must anticipate.

The problem with lack of instruction on how to disclose is illustrated when women in the support group express their need to 'predict the future.' Like the women in the Doyal and Anderson (2006) as well as the Kimberly et al. (1995) studies, disclosing to elderly mothers was a source of great anxiety. There is an expressed fear that the disclosure may kill their mothers who may also be living with their own social as well as health problems. The related fear of disclosing to children is also a complex one. The

women in the present study grappled with the dilemma of wanting to disclose their status to their children and their fear of the subsequent stigmatisation of their children who may or may not also be HIV positive. This finding of fear of their children experiencing rejection is supported by similar findings in the Scrimshaw and Siegel (2002) study of American women living with HIV.

For the women in this study, making the decision to disclose their HIV status is confusing and at times impossible. The medical and psychological establishments as well as the HIV activist community are putting the pressure on to disclose in order to gain social, material, and medical resources, make changes in the way society sees people living with HIV, and also as a catharsis. However great the gains may be, disclosing is easier said than done. The women in this study point out that it is not always possible to disclose publicly, especially if there are no support systems in place to facilitate successful disclosures and the difficulty of predicting the reactions of the loved-ones they may choose to disclose to. However as we will see in the next section on doing care work while facing abuse, disclosures are not the only worry the women in this study have regarding their loved ones.

4.3 The Complexities of Care Work versus Gender-Based Violence

The women interviewed speak frequently of work in general, and about care/social work in particular. Many of the women in this study fear for their own day-to-day survival in terms of just finding enough food to eat each day and not suddenly dropping dead of HIV (several women express this as their greatest fear). Despite these real concerns about themselves, these women speak of also taking responsibility for and

taking care of their men partners and children. Their discussion of care work is further ironic because in the interviews most of the talk about men is a discourse of abuse. Women however, draw on discourses of femininity in describing how men need their care, despite the abuse they inflict. Some also go a step further in explaining how being a 'proper wife', which includes caring for man's sexual needs, has taken a toll on their physical health. The following excerpts illustrate the women's struggles to take care of men and children, many times in the midst of an abusive relationship.

Shareen's trouble started when she got married two years ago. A short time into the marriage she found out about her husband's positive status while she visited him in the hospital. There, she took the liberty of reading his medical chart at the foot of his bed. The chart listed him as an HIV positive patient. Once she read that he had tested positive, she believed it necessary to have herself tested. Here she explains how painful it was to get tested secretly and alone while he was in the hospital:

I go to the 14th of December and the doctor took my finger and he didn't say—the sister didn't tell me I'm HIV the same time. [S]he told me I must go to the other room with my file and I see on her face there is something not right. And she asked me, "Shareen, if I told you you are HIV, how would you feel?" I didn't talk ... I told the sister,

"But you must tell me now the truth if I'm HIV or not."

And she say to me, "Shareen, you are HIV positive." [pause] And I sit there and I hold my head and I take my hair and I do like this [pulling] and I put my head behind the wall. And I start crying, crying, crying.

Shareen explains how her husband was physically abusive to her. After finding out about her status, Shareen became pregnant before she could get an appointment at the clinic for birth control because she says she had decided not to have any more children because of her positive HIV status. She says she tried to get an abortion but was refused at the clinic on the grounds that her husband was not present for the procedure. Shareen

further explains, however, that the unexpected pregnancy has benefited her: “My husband was very happy. [pause] Because I had ... for, for, for a year and 2 months my ... my life wasn't right. Every 2 days my husband hit me. And now the baby's here and he's happy and he don't hit me anymore.”

Shareen confronted her husband and he admitted to having known his status for a long time. His family also knew of his status and she confronted them as well during a visit with them in another province:

...I ask his mother why she didn't tell me that her son was HIV positive. She told me if she gonna tell me, I'm gonna drop her son. I say, “No I don't wanna drop. I also now have the same virus he have.” And now my mother-in-law told me if I don't want her son anymore about this, she don't want—I must go and leave—I must leave. I say, “No I love him. I'm staying here by him. Fight with this together.”

She say, “Ok if you're like this, you can stay.”

Here, it is important to explain the manner in which Shareen speaks about these events in her life. She speaks quietly and with a certain numbness. In spite of painful obstacles like receiving a positive HIV test, being infected by someone who knew his status and claimed to love her, being refused an abortion, and being physically abused, Shareen has decided to stay with her husband who is frequently ill and “fight this together.” It is important to note that Shareen considers herself a religious person and claims this has shaped her thinking and behaviour in regard to her husband. Besides staying with her husband because he is physically threatening and there is nowhere else for her to go, Shareen also expresses the notion of religious forgiveness for the abuse (Boonzaier & de al Rey, 2004) and this may be an additional force that is drawing her even closer to her husband.

Because Shareen's husband is quite ill, she may also be expressing the idea that care work for dependant men is a behaviour expected of women and from a feminist point of view, these expectations or forced behaviours are what maintain and support the patriarchy and subsequently the justification of woman abuse (Dobash & Dobash, 1979, as cited in Boonzaier & de la Rey, 2004). Because of the way in which oppressive gender has been constructed for women living in the patriarchy, care work is a type of work women are compelled to do, for the survival of others as well as acceptance in society. In fact, many women define themselves in part by gender expectations for women in their ability to provide care and put other's needs before their own (Gunsaulus, 2006).

Priscilla is also a woman who was infected by a partner who was aware of his positive status beforehand. She speaks of her partner's blasé—almost cheerful attitude towards her positive HIV test:

So he asked me, what did the doctors say, you know, with a smile on his face ... And I was so scared to tell him because I thought he's gonna leave me—maybe it's me with the virus, whatever But my main problem was, "You gave it to me! You gave it to me!" And umm, I talked to him, "I'm HIV and ..." You know I didn't talk to him like I'm talking to you now. I was screaming and yelling and crying in between ... and he said,

"Oh well, accept it Priscilla, because there's nothing that anyone can do ... but I'm gonna show you how much I love you," and he make love to me without a condom.

It is important to note that Priscilla speaks of this incident repeatedly (field notes, August, 2006) and in these conversations she reiterates the fact that she did not want to have sex without a condom at that time. Significantly, she refers to the incident as "making love to me" which may be a reflection of her constructing the event in such a way she was the submissive and passive party in the incident. These constructions of "male sexuality as active" and "female sexuality as passive" by women who were in

abusive relationships were also evident in the Boonzaier and de la Rey (2004, p. 458) study. Additionally in her labeling the incident as “making love,” (which usually connotes consensual sex) further reflects the findings in the Boonzaier and de la Rey study in that women may be reluctant to label violent incidents such as this as rape. This may be because women in marriages or other types of marriage-like relationships give in to or feel that they are obligated to be sexually available to their partners at all times.

Priscilla speaks more of the physical and psychological abuse she has endured with her current partner. She has extreme anxiety over her partner’s refusal to discuss the fact that he knowingly infected her and how he became infected with HIV in the first place:

Because I just wanna know who gave it to me that’s all. You know I read last night a *Drum*¹³—it’s not time to blame each other about this virus ... if you find out you have this virus, just accept it. Don’t blame him. Don’t blame her. That is what I read in the *Drum*. But I don’t know, Anna ... I just ... I think I just need some answers ... You know, Anna, if you don’t even tell me about the virus, then don’t talk to me. He don’t talk to me He just lay in the bed, give his back to me ... Don’t talk to me. And I think that is also the problem, because he don’t talk to me, Anna.

She also speaks about an incident in which her partner became intoxicated and tried to kill her so he could be with another woman:

Anna: Has he ever been violent?

Priscilla: Yes...

Anna: What did he do?

Priscilla: He was drinking and he was locked the door and he wanna ... what is that? ... how do you call that? ... I don’t know what do you call that in English, that you cut a hole ... not a hammer ...

Anna: A saw?

¹³ *Drum Magazine* is a South African magazine that was launched in the 1950s and targeted Black audiences. Today the magazine is still popular among a variety of audiences although its content is less political than it once was.

Priscilla: Yes a saw. He locked the door and then he will saw me [laughing].
Honestly, ask Anna.

Anna: Did he cut you?

Priscilla: No.

Anna: But he tried to saw you?

Priscilla: Yes because Nazeem was there to come and fetch me. Not last year ...
the year before.

Anna: Why did he ... because he was drunk or ...?

Priscilla: He was drunk and I think he got someone else, but I was in the way. So
I told Nazeem he must come and fetch me. And he came and fetched me and he
took me to my sister. And he never drank again. That was the last. It isn't so, you
know ... so cute. There's also problems ...

Priscilla has expressed great anxiety over her need to know how she became infected and over the fact that her partner perpetrated repeated acts of infidelity during the course of their partnership which she believes, resulted in her HIV infection. The idea that infidelity on the part of a man as a form of woman abuse is not an idea that has been explored by scholars until recently. Boonzaier (2005) noted the emergence of infidelity as a form of control and abuse in her interviews with women in South Africa. Women in the present study frequently mention infidelity on the part of their partners as major a source of anxiety and as a possible reason for their positive HIV status. This reasoning is supported by Dunkle et al.'s (2004) findings in research done in Soweto that women who report abuse in their most recent relationships with men are more likely to be living with HIV.

Priscilla has also tried to end the relationship each time her partner leaves her to be with other women. Here she explains their on-again off-again relationship:

...every time he told me he's got someone better than me—then I put him out. Then he comes back. Every time it goes like this. On and off, on and off. So I told him, "No man. It can't go on like this. I'm getting older, my kids are getting bigger. I think you must go." And I put him out and I took his stuff and I threw it

out. So he went. He go and 2 months ago, he came back to me. He crawled and cried and pleaded,
“Please Priscilla, take me back. Please? I’m asking you nicely.” I mean, Anna, I was feeling so ashamed, you know? I asked my daughter,
“Can Mommy give Darryl another chance?” So she said,
“God gives you another chance, so why ... but this is his last chance. Mommy just tell him.”

Although these experiences appear to warrant leaving the relationship, the women I interviewed are in a unique predicament. Attempts to break away from abusive partners may be impossible because of threats of physical harm as well as other forms of manipulation. Furthermore, they may not be able to sacrifice the social ‘privileges’ associated with having a man, especially when these women are already marginalised because they are living with HIV. For these reasons, the women are forced to embrace hegemonic, oppressive constructions of gender in hopes of legitimising the abusive relationships.

Priscilla, like Shareen, is also willing to give her partner more chances. She speaks about him with hatred but also with pity and empathy as they are both experiencing many of the same physical and emotional problems related to the HIV. This discourse of HIV positive partners among these women creates a kind of romanticised version of living with the virus and staying with the partner who is abusive and from which she became infected.

Elvyra has also experienced abuse from her husband. Elvyra reunited with her ex-husband after 30 years of being divorced from him. Her husband has known about her status all along, but he refuses to get tested or use condoms. Here she explains the problems he has with condoms:

So we got married and we living together now. And so I said to him, “Anyway, I don’t want you also to get sick because then we both is gonna get sick. We can’t look after each other. Either you must use a condom ...” So he said,

“No.” he’s not gonna use a condom ... he’s not gonna use a condom ... Anyway sometimes ... then I ask him,

“Are you sure you don’t want to use a condom because maybe you want to ... you must go for a test?” So he said, no, why must he go for a test, because he loves me and he wants to be with me and why must he ... why must he use a condom.

In the above excerpt, Elvyra draws on the dominant discourses of “getting tested” and “using condoms” perhaps because she has trained as a peer counselor for HIV positive people and her training may reflect these dominant discourses. Despite her training, she suggests that she is unable to convince her husband to take action for the sake of their own health. Not only may his refusal to be tested or use condoms endanger Elvyra’s life further, he also uses his refusal to use condoms as emotional leverage in the frequent arguments they have:

Yes sometimes we say words to each other but there are some times he say he offered his life for me. That I can’t understand because now the other day I told him, “You were told. It’s not to say that I didn’t tell you. At first I told you about my status. It’s your choice, so why did you stay? So don’t come and throw it in my face now because it’s not gonna work.”... Every time ... maybe if we get an argument. Every time then he will say just,

“I offered my life for you.”

Elvyra’s husband is inflicting abuse on her in his non-use of condoms and in his refusal to get tested for HIV. In this way, he may be able to keep her in the dark, within his control, and indebted to him. Even worse, he has constructed himself as the victim when he states that he has “offered his life.” Male perpetrators constructing themselves as victims is not an uncommon strategy men use in displacing blame as it was a strategy also used by men in the Boonzaier and de la Rey (2004) study. This implies that Elvyra

has infected him with HIV, when in actuality, he may have forced her to by refusing to use condoms.

Elvyra may have feelings of being indebted to her husband and at the expense of the support of her family. Elvyra said she initially left her husband 30 years ago because he was abusive. Now she talks about her family's reaction to their recent reunion:

They knew him that time that he was mos¹⁴ umm ... he was very weird that time. He was abusing me that time ... Maybe I think they disappointed because I take my ex-husband back that I got now. They are very disappointed, I think that. Because on the end of the day, who will support me? Will they support me? I mean he's working in the house. He's helping me. He put food on the table—are they gonna do it? But they never come to me and ask, "Elvyra how are you feeling? I hear you sick ..." or so.

Elvyra is defensive about her reunion with her former abuser. In spite of what she describes as a deep need for her sisters to return their affections to her, she has chosen her husband over her family. She claims this is because of the care and financial support he offers, but later in the interview she describes another reason for her choice:

Yeah because at this moment I also got stress. And umm ... because my husband is smoking drugs. And you know if he brings money home every time he asks me, "Give me money," also. But I just pray that I don't want to upset myself anymore or work myself up because then I'm gonna be down ... I'm attending a campaign now. At the moment it's still Sunday night. So the pastor's helping me pray ... that he must leave the drugs. We are on that now. On his case. Because that's all stress I've got now. At the moment ... he want money now or they must smoke now. And that I can't take. And then I just say,

"Here's a 20 rand. Just go smoke, but leave me out. Because I want to rest. I want to read my Bible or I took a class or something."

The above excerpt is in contradiction to Elvyra's earlier reasoning of staying with her husband because of the support he provides. Here she shows that the exact opposite is

¹⁴ "Mos" is an Afrikaans exclamation.

the case—Elvyra seems to be saying that she stays with her husband because *she* is able to offer *him* the care and support that he needs.

Elvyra has seemingly chosen to look after her husband—former abuser—who now has an expensive addiction. In the next section of the interview, her choice is at the cost not only of increased anxiety and decreased social support from her family but also of her own fragile physical health

We mos seldom get shingles right? Seldom that you get shingles. In last year, late in last year I had this stress from this husband of mine. So my whole body was full of shingles. I didn't sleep for 3 months. So I went to the day hospital. So the doctor just lift up my top. So he said, "My good grief! Elvyra, how did you sleep because this is a painful thing!" So they bandaged me from here till here (waist to under breasts).

Elvyra too has taken on the responsibility of caring for and attending prayer groups for the sake of her husband who was and still is abusive to her. It is possible that taking care of her husband, because husbands are constructed as partners with whom women must stay with, endure abusive treatment from, and care for, takes precedence over other issues in Elvyra's life. Women in previous studies (Urdang, 2006) as well in the present one feel that in order to maintain their identity as good women and good wives they must take care of men partners and husbands even if the man is abusive and even if the woman can point to specific ways in which her health is suffering because of the care work she is doing.

Sonia avoids speaking about why she is separated from her husband—she only mentions that they split during her pregnancy with their child, who is now eight years old and living with the virus as well. She hints about him being obsessive and jealous and also talks about having taken him back several times against her better judgment:

... like with my boyfriends, I have a rule. I didn't tell them. I give them three chances and once ok, and twice ok I give, third time? Gone. My husband got seven because he's my husband. I gave him seven chances. He blew all seven chances.

Despite the nature of the problems they may have had, she explains her choice to continue to offer support to her husband. Sonia's use of the term "husband" in her talk is specific and significant. She has constructed her husband as quite different from a partner or boyfriend in that she may be required to give him "more chances" and endure so much more.

Below, Sonia describes an activity in one of the support groups she attends. The activity was one in which each member had to stand beneath a photo that represents their feelings. This was the day she decided that she could not abandon him completely:

... And, and it was very heart-sore. And I think that's why I'm still so close to my husband because he's also positive. I'm not sure if I gave it to him or if he had it before—that I will never know, but he was sick when I met him. And umm in any case ... the thingy is they were standing around and he went to go stand by the picture ... the mother, the father and the child separate. And I knew there and then that I couldn't leave him like that—irrespective how I feel about him, he's my brother. In spirit he's my brother and I can't desert him. I can divorce him, I can do whatever, but I can't desert him. So, that's why I won't—I don't think I will ever be able to break that bond with my husband. He wants more. He wants me to be back with him and that but I ... I'm not up for that.

Although Sonia expressed an interest in being interviewed, she has left out certain parts of her life in the interview and it is not clear whether or not her decision to not "desert" her husband has been at a cost to her emotionally or physically. Nevertheless, she has taken a man who 'blew it' seven times, back into her care and she seems to describe it as an act of sympathy and love. Sonia speaks of the sympathy she feels towards her partner who is also living with the virus as well as seeing a need to care for him or that she, "can't desert him." Perhaps her husband would have neither

psychological nor material support without her. As in the Boonzaier and de la Rey (2004, p. 454) study, the way in which women speak about their sympathy and their need to do care work for their partners, the line between “wife” and “mother” has become blurred.

Elaine also speaks about caring for a person who was previously abusive to her. She had an ex-boyfriend who took advantage of her. Here she explains the nature of their relationship:

I had a boyfriend and this boyfriend used to be so abusive with me. He had other girlfriends also, but I was oh ... the way I with him, I like him a lot. I was ... even with him when I like him a lot ... on a Saturday morning I don't have any money—we spent all our money. Cause he don't work, I was only working—he didn't. All my money's out. I don't have food in my house.

In this instance, Elaine specifically cites infidelity as a form of abuse that she had to endure and it was the price she had to pay to maintain the relationship with her boyfriend at the time. This same man she so admired, disclosed her HIV status to other women in her block of flats. In addition, Elaine alludes to him forcing her to have sex in this section of the interview:

But he was very nice when he was sober, but when he's drunk ... He used to ... he wasn't so ... with me he wasn't violent, but he just want to have sex. That's all he want. He wasn't violent and he likes to drink. If I haven't got money, then I don't see him. But when I got money, then I see him. He was like that.

Elaine, like Priscilla, stops short of accusing her ex-boyfriend of raping her, but what she is describing appears to be repeated coercive sex bordering on rape. The ability of women to name the abuse they have experienced may be linked to public awareness of the issue of gender-based violence (Boonzaier, 2001). The forms in which gender-based violence come in may not be the forms that are widely publicised. Thus, women may not identify an instance of abuse as true abuse, simply because it was not ‘violent enough.’ In

addition to Elaine's boyfriend "just wanting to have sex," it seems he has also perpetrated acts of economic violence against her. In many instances, economic abuse results from a woman's economic dependency on men (Hoosen & Collins, 2004) which gives the men leverage and control in a relationship. In Elaine's case, her boyfriend was spending all of her money that may have otherwise gone towards herself and her children's needs. It seems that Elaine carried on in this relationship in order to keep her partner in her life which may have been a much-needed source of normalcy for her.

Elaine now has a new partner who she claims is quite supportive and caring. She and her current partner heard about an accident that her ex-boyfriend was in and she talks about her visit to see him after his accident:

Me and my boyfriend that I have now was there by him last week. Here in the holidays we went to him—he had an accident ... I was there by him in the hospital. It was a car accident here on Grand Road. But he had a hole here in his head. His neck was broken in 3 parts. He's now so thin. I said to my boyfriend, "He's so thin. He's not that person he used to be." He used to shave nice clean. Head is clean. Nice clean clothes on. But now he stink. He's brown, brown, brown. I said, "You know what, when we come back again we gonna buy you some stuff. Shaving stuff and soap." Because now he's staying with his mother and he said his mother is the only person that work and he get disability. I say, "What you doing with your disability? But we gonna buy you shaving stuff, soap, toothbrush and toothpaste and you must clean yourself ... You aren't that person you used to be."

Elaine has sympathy for and has decided to care for the ex-boyfriend now that he is in a desperate situation even though he used to spend all of her money, and possibly abused her sexually.

Remarkably, some of the women I interviewed speak of still caring for men, in part, as a passport into normalcy even when the men for whom they are caring are abusive and a financial burden. More specifically, in the context of South Africa where men are often chronically unemployed, women are frequently the sole breadwinners of a

partnership (Boonzaier, 2005). Boonzaier and de la Rey (2004) found that because of this gender reversal in which women are the primary breadwinners, men claim to feel emasculated. Some men in their study express their frustration with their inability to carry out their 'proper' gender expectations which they say leads to instances of violence against their women partners. One way of explaining why the women interviewed stay in non-beneficial or even abusive relationships is that the women need men as a 'gender prop,' so to speak. Meaning, women need men to maintain the veneer of normalcy for themselves as well as society, so they must oftentimes settle for and take care of men who are less than supportive, caring partners. But the job of care-taker for these women, does not end here. There are other people in their lives that they must also take responsibility for.

4.3.1 Doing Care Work for Children

Women also do care work for their children. This investment of time and energy, however, may have a material return. Sometimes women are able to benefit in some ways from care work done for children because their children learn in turn to care for their mothers. This is evident in previous research findings that show that children have a lot to do with the decisions women make about their lives and that children do play a positive role in encouraging and helping their mother's adherence to ARVs (Wood, Tobias & McCree, 2004). These findings are reflected in the women in the present study in that some children take an active, positive role in helping their mothers adhere to ARVs and in the women's determination to equip their children with skills for care work. However, for other women, caring for their children in the ways in which expectations about femininity and especially mothering call for, much less providing for their children's

basic needs, is nearly impossible. And this impossibility is also a contributing factor to a woman's stress level and an ultimate decline in her overall health. Evidently, the benefits--or necessities--outweigh the risks to health because a woman who does successful care work is able to still think of herself as a 'decent' woman and a loving wife and mother despite the fact she has been marginalised because she is living with HIV as well as various other oppressive forces in her life.

Priscilla is the woman who speaks the most about the considerable worries she has about taking care of her children when she "finally gets sick." Priscilla begins talking about caring for her children in response to the first interview question about when she first found out she was living with HIV:

I've got four kids, the eldest one is 15 and 10 and 6 years and 2 years old—I don't know what's gonna happen to them, you know? There's a lot of things on my mind. Every time I just think, "Oh god! What's gonna happen to them when I'm dying?" because this illness is ... I don't know, Anna, but my worries here is I'm going to get sick—I *know* I'm going to get sick and I ask god to fight and to keep me strong because I don't know what's gonna happen to them—especially to my baby ...

In another part of the interview Priscilla again emphasises her stress over not being able to provide properly for her children especially her oldest daughter:

I would like to earn something because I got a 15 year old daughter, you know, Anna, she wants pants for Christmas. I don't have that kind of money. It's R750. I don't have that money. Because her friends are wearing names, you know. And she don't understand.

Priscilla feels that because of her HIV status which has lead to her inability to find a decent job, she is unable to provide for her children properly. She repeatedly cites this as one of her greatest sources of anxiety.

Elaine also speaks about taking care of her children. In this section of the interview she explains one of the reasons she decided to go on ARVs despite hearing

horror stories about them. Here she relays what she said to her sister who is a nurse and was warning her against taking ARVs: “I’ve got children that I must look after. Nobody’s looking after my children. Who’s gonna look after my children?”

And Elaine speaks again about caring for her children in another part of the interview talking about her struggles to buy food for her children:

Even at home also—if there’s no money, there’s food. I don’t worry. As long as I’ve got food in the house, I don’t worry. Why must I worry? The children ask me, “Mommy, what are we gonna eat tonight?” I say,
“We just eat that what is there. If you must eat potatoes, you just eat potatoes.”

Elaine says “why must I worry?” but clearly she is worried about providing food because she tells her children they must eat what is available, if there is anything available at all.

Elaine also speaks about care work as it involves her children caring for her in return. Here she speaks about when she disclosed her positive status to her children. Her youngest daughter began to cry and she explained how it was no time to cry, but to begin learning how to do care work:

“Mommy’s not gonna die. If Mommy gets sick Mommy must go to the hospital, to the clinic. This is Mommy’s tablets that Mommy must use. Mommy musn’t forget to drink these tablets. *If* [emphasis in the original] Mommy forget, you must remember Mommy every time, ‘Did Mommy drink tablets, or did Mommy not?’ Then will Mommy drink and Mommy will tell you ok. Or Mommy forgot something and then you must come and remind me.”

In the above excerpt, Elaine seems to be reviewing the steps to care-taking with her daughter and possibly teaching her a care-taker’s duties. Besides Elaine, other women

interviewed speak about teaching their daughters to do care work, however their efforts are not always successful.

The ways in which the women interviewed speak about their children, especially their daughters, in regards to caring for them and the problems they face in doing so are significant. Although interviews were not conducted with the daughters themselves, the women spoke about frustrations they have with their daughters. Schrimshaw and Siegel's (2002) study on the effects of mothers' disclosures to children illustrates the differing reactions children have. Some of the children in their study reacted by becoming closer to their mothers, while others reacted negatively, blaming their mothers and exhibiting behavioural problems. Several women in the present study spoke at length of their attempts at teaching their daughters to do care work and how their attempts have been riddled with obstacles.

Sonia struggles to take care of her children. Her oldest daughter resents her for this and for contracting HIV, but here she speaks about the care work that her second oldest daughter is learning to do:

My eldest daughter, we have so much problems I can't ask her to be my treatment buddy¹⁵. Would you believe me Anna if I tell you that Delia (second oldest daughter) is reminding me when we at home, everyday, "Did you drink your tablets? Did you drink your tablets?"...

I mean. She's 13 years old and she's reminding me and, and that is the thingey that my eldest daughter should be training herself to do already.

Above, Sonia appears to be illustrating that her second oldest daughter knows her 'duties' as a care taker in making sure her mother has taken her tablets.

¹⁵ A treatment buddy is a friend or family member who is involved in reminding people to take their ARV medication.

Sonia seems to be frustrated with the fact that she cannot provide and care for her daughters in the ways in which she would like to. She reiterates this point when she answers the question of what her greatest fear or worry is since being diagnosed:

My biggest fear is that I should die without making proper provision for my children. Because I'm now in a very, very cheap burial society that's the *PEP*¹⁶ insurance at the *PEP* stores. I don't have additional insurance to fall back on. Umm, my children isn't in a proper house; umm, their education I'm also worried about because anything can happen; umm, who is gonna be my little one's guardians if I should die before they the age of consent; umm, who's gonna be my treatment buddy when I must go on ARVs. Umm, all that type of fears I knew ... I also have my fears. That's--that's my fears.

Sonia has listed her duties as a care-taker. Although she is saying that her children's housing, education and future guardians need to be in place in the event of her death, she has very little support. She may be listing these duties in the form of an inventory of her "fears" because they are seemingly impossible given her circumstances.

Denise also expresses severe anxiety over her inability to care for her children in the ways in which she sees necessary. Denise is unable to find steady work and has gotten fired from jobs because she falls ill and has to leave work and take days off to visit doctors. Here she explains how she is unable to care for her daughter in some very basic ways:

... everything is difficult ... everything is difficult because I can't do ... [unclear] ... sometimes we sleep without food ... [unclear] because that's why because she is on school ... sometimes the children are at home ... and then this year I didn't pay school fees for her ... I didn't do anything ... Lot of things, lot of things ... what am I going to eat today, how my child is gonna go to school, plus I don't have money for transport. You see? How am I going to wash my washing, just like that.

Denise's language usage above, such as the repetition of "everything is difficult" and "lots of things" serves the function of emphasising her overwhelming difficulties and

¹⁶ *PEP* is a retail chain store in South Africa that sells clothing and household goods as well as cell phone contracts, life insurance, and burial schemes.

despair in her situation. Denise has also attempted to teach her oldest daughter to help in the care work she needs but to no avail. Her 16 year old daughter is her greatest worry as she is possibly having unprotected sex with her boyfriend and she refuses to do housework:

Denise: And it's only me and my daughter.

Anna: Does your daughter help you?

Denise: She like to be on the street ... She don't even like to cook—she's--she's 16! She's turning 17 this year October ... Worried about what my daughter's doing. Bringing the boyfriend in the house. Sleeping with the boyfriend in the house. You understand that?

Anna: Has anyone ever helped you with any of those problems?

Denise: No. No people just talk behind me. Can't tell me straight, "She let that boyfriend in the house ..." I don't--I don't like it ... just because I don't like to talk because she's gonna say I'm giving her a difficult life. You understand? She don't understand this ... she--she [crying] you know, stressing me.

It becomes apparent that although Denise may have tried to teach her daughter to perform care work, her daughter has resisted. Denise is suggesting that it may be impossible to convince her daughter to help her, because her daughter resents her and may feel that Denise has, "given her a difficult life." Denise is scared for her daughter's as well as her own well-being but she says she feels that she has come to the end of her rope. She cries when she speaks about the problems she has with her daughter, she also speaks in a very dejected way and has mentioned leaving her children and relinquishing the job of care-taker to her best friend or grandmother.

Some women describe problems they have had in providing their daughters with basic necessities and their daughters' negative reactions to this. Between the descriptions from the women interviewed and the casual conversations I had with several of their daughters, there seems to be an underlying resentment or blame for the condition of HIV in their mothers, on the part of the daughters (field notes, January, 2007). Children

placing the blame for becoming infected with HIV on their mothers, is a reaction seen in the Schrimshaw and Siegel (2002) study as well. Scrimshaw and Siegel also note that some children see their mothers as responsible for the 'mess' that they are all now in. It appears that the daughters of the women in the present study see through and/or are critical of their mother's behaviour in terms of caring for or being involved with men who are detrimental to their lives (and who may have infected their mothers). As much as the mothers want their daughters to conform to the care work role, the daughters continue to resist, sometimes benefiting from this and sometimes to their own detriment or the detriment of their relationships with their mothers.

Salo's (2005) research in Manenburg, a community similar to the one in which the present interviews were conducted, illustrates the gender norms in this community in which older women teach their daughters acceptable gendered behaviour. These expectations include women behaving in modest ways in terms of dress, not venturing outside the house without an older woman or for no particular reason, and taking responsibility for their domestic chores (which includes care work). Salo goes on to explain that these gender expectations for women are starting to erode as young women search for new identities (for better or worse) in post-apartheid South Africa. These findings may be related to some of the problems the women I interviewed speak about concerning their daughters.

It is apparent that taking care of daughters in particular, is a struggle in that these young women are resistant and wary of repeating the patterns of their mothers and that they place blame on and stigmatise their mothers and the virus they are living with. There is an element of hope however because although the daughters of the women may

not always be doing what is best for themselves and their mothers, at least they are resisting. It is important to note that although the possible resistance of hegemonic gendered behaviours on the part of daughters is positive step, it is not however a justification of the blame and stigma that they may place on their mothers. Nevertheless, there are indeed daughters who are resisting or rebelling against their mothers and in doing so, are rejecting some of the gender hierarchies that have failed their mothers.

The dilemma women face in providing care and social support is complicated and multifaceted. The women interviewed explained how they must care for men and children while many times enduring acts of abuse at the hands of the men they are caring for. It appears that women are compelled to perform and emphasise their gendered duties of 'self-sacrificer' and 'care-taker,' often to the detriment of their own health and well-being, in order perform necessary care work as well as to point out that they are 'proper' women despite the fact that they are living with HIV. The ways in which women speak about care work done for their man partners and children indicate that the hegemonic constructions of gender that women are relying on for acceptance and survival are not working and unfortunately this normalising tool is a strategy by which the patriarchy keeps women in their place and legitimises their oppression and abuse.

4.4 A Woman's Body

Nowadays with proper care and the use of ARVs, if they are available, HIV can be treated as a chronic illness. Nevertheless, the virus is still portrayed in a frightening way by the medical community and especially by the media. Healthcare workers, the community, and the media still refer to this virus as AIDS, a word associated with an

image of an emaciated person dying in a hospital bed (Whittaker, 1992). In addition, because of the lack of access to treatment or ignorance about seeking treatment, being HIV positive for many is not a chronic condition and the frightening images mentioned above are not far from the truth. In South Africa, as well as many other countries, people are visibly dying from HIV and the media and medical establishment have publicised and emphasised this visual. In addition, there are other forces from the West and historical events that may also have an influence on the social construction of body ideals and the way women see and experience their bodies.

Body image and beauty standards for coloured women in South Africa are complex as it appears in the present study, in their need to adhere to Western standards as well as appear to weigh enough to appear healthy as seen in rural Jamaican women (Sobo, 1994). However there is a gap in the literature concerning beauty standards and body ideals for these women. One of the possible roots of the standards emerged from the cultural mix, tensions, and oppression of long years of slavery and apartheid in South Africa. White European colonial slaveholders' beauty standards were valued in much the same way as they are today as well as in the rest of the world. In addition, historically, South African women's bodies were dissected and analysed under the lens of racist European colonists and their sets of standards. This idea is exemplified in the story of Saartjie Baartman. Saartjie Baartman was a Khoisan woman from South Africa who was taken from her home to Europe by British colonists in 1810. Baartman was coerced into traveling the world with her exploiters to display her body to white Westerners. European voyeurs dissected and exploited her body in attempts to defend racist assumptions about and to sexualise African women (Wiss, 1994). As well, she became a visual fascination

for white Europeans because they believed she did not resemble them or their ideals of white beauty. Clearly, South African women's bodies have a history of being othered for reasons of race and nationality. The othering process is compounded by 'disease.'

The discourse of expectations about beauty and women's bodies emerged as a significant one in this study. The women talk about their bodies and their beauty in three main ways: 1) How she used to look before finding out she is living with HIV; 2) how HIV has made her and positive people in the media look; and 3) how ARVs make her and others taking them look or how she thinks they will make her look.

When asked about how life has changed since receiving a positive HIV test, women talk about what they looked like before they were tested for HIV. Priscilla talks about how her daily struggles for food and money have been magnified since she found out she is living with HIV. She reminisces about the days when she still had time for herself:

I totally changed, Anna. I totally changed, honestly. And you know, I don't even have time for myself. You know? Before I found out I'm HIV, I was always ... how can I say? ... If your hair is beautiful, then your face is also beautiful. My hair was always rolled in, you know. I was always looking to myself. But the moment I found out, I lost totally control. I'm not the same person...

In her use of language such as, "I totally changed" and "I'm not the same person" in reference to her physical "beauty," Priscilla suggests she is not who she once was. In addition, her words allude to her feeling that because her appearance may have changed, it is possible that her entire *person* has changed. This suggestion is quite drastic because at the time of the interview, Priscilla had only known of her positive status for about one year.

She goes on to speak about feeling torn when people compliment her nowadays. She describes how some people in her previous neighbourhood reacted and how she felt when she went to visit after a long time. In this portion of the interview Priscilla claims to feel good on the one hand because of the compliments, but on the other hand they also elicit negative feelings she has towards herself about harbouring the secret of living with HIV and in some ways she suggests that she feels unworthy of the compliments:

But to tell the truth, Anna, that is what I think of myself. I'm not that person anymore and I don't look cute or whatever. But when I go to people that they don't see me for a long time, they always tell me, "Ooh, you are just the same. You are cute! You got a lekker figure." You know—so. I can't believe that the people said I look so cute and so sexy. You know, I will think a lot of bad things about me because I'm HIV.

Here again, Priscilla uses the phrase, "I'm not that person anymore," in reference to her physical appearance. But is it possible that her words signify something more because at the end of the excerpt she states that she, "think[s] a lot of bad things about me because I'm HIV," which suggests she may feel unworthy of compliments for feelings that go beyond frustrations with physical appearance.

Linda also talks about how her body used to look before she initially lost weight and found out she was living with HIV and the subsequent change in body shape she experienced because of the ARVs:

... because I used to wear size 36 ... those flair skirts I never wear now anymore, because I don't have hips anymore, I don't have bums anymore (laughing)! ... I can wear other clothes. I've got clothes that I didn't wear anymore ... You know, the next meeting I'll bring you my pictures that I took when I was size 36.

In the above excerpt, Linda points out that she does not, “have hips” and she does not “have bums” due to side-effects from ARVs. Her words suggest a dissection or a disconnection of the parts of her body she is not happy with or that have changed and her self. This dismemberment is a reflection of objectification and commodification of women’s bodies in Western advertising media and pornography (Kirk & Okazawa-Rey, 2004).

Elvyra speaks about how she used to look as part of her response to the question about what the biggest changes in her life have been since being diagnosed as HIV positive. She explains how she used to be involved in several different sports and her diagnosis caused her depression and the cessation of her athleticism:

Elvyra: I played badminton and all that. Yeah! I was a 60 [kilograms]—my weight was 65 ... 68. Yeah. Yeah. And badminton. I played badminton.

Anna: Why did you stop ... being athletic after...

Elvyra: Because I felt very disappointed. Because you don’t feel active anymore.

The mention of her weight is significant here, because Elvyra is now quite thin. Although a weight of 60-68 kilograms is not heavy, it is still probably more than she weighs now. She expresses her “disappointment” that her athleticism has waned. In addition Elvyra is explaining that her body is not one of an athlete as it once was. While some of the ways in which these women speak about beauty ideals and maintaining their beauty seems to reflect expectations of the global West, the ways in which they speak about body size and weight are not.

The West, primarily the United States, is arguably the source of some of the most stringent and enduring, thus hegemonic, body and beauty standards for women. The

white-supremacist, capitalist, patriarchal, Western system expects women in the West to uphold a certain set of extreme physical characteristics (Kirk & Okazawa-Rey, 2004) that may in many cases only be obtainable through surgical procedures, in order to gain entry into society and access to men in particular. The most prominent feature of these sets of standards, is the necessity of having a body that is as thin as can be. In the West, a woman's thin, specifically proportioned body is a mark of her morality and her will to exert self-control (Bordo, 1993). In addition to signifying her drive for success and mastery over her body, the necessity of thinness draws on the increasing bio-medical discourse surrounding the array of purported health risks associated with being 'obese' (Huff, 2001). However the ways in which the women in the present study speak about their concerns over their loss of weight due to medical problems or stress, reflects a different set of standards. In research with women in rural Jamaica, Sobo (1994) points out that the bigger a woman's body is, the more beautiful and healthy she is considered. The women in the present study may be suggesting that they need to appear weighty enough so that it does not appear that they are unhealthy.

Western expectations of thinness in women could arguably be a more exploitative ideal than the larger body ideal for rural women in Jamaica, however women are compelled to have to appear in a certain way one way or the other. It could be said that the very notion that women *must* appear in a particular way is a Western one. And increasingly, these Western beauty standards and expectations of women are becoming more common for women globally (Kirk & Okazawa-Rey, 2004), specifically in the global South. Images of beauty and body ideals are disseminated throughout the globe in the form of media so that the rest of the world can see and process the images and

incorporate them into their own cultures as well (Zezeza, 2002, July, as cited in Salo, 2005). The media industry in the United States as well as Bollywood from India (which reflects many of the same components of Western beauty ideals) and the media images of beauty these institutions pump into South Africa cannot be ignored by women. These beauty ideas fuel patriarchal, capitalist societies in that women are compelled to consume a variety of goods and services that facilitate these ideals (and if they cannot, they are marginalised further) that simultaneously economically support capitalism as well as maintain the oppression of women under the patriarchy (Kirk & Okazawa-Rey, 2004).

The women I interviewed are aware of how people living with HIV are portrayed on TV and in other media. The women talk about the physical appearance of people living with the virus on TV and how those images have affected how they see themselves.

I asked Tisha how she came to the decision to take ARVs. She tells me about how she needed treatment because she was physically ill, but what really motivated her to take the plunge were the images she witnessed on TV:

I had to take the tablet for my ... see because I was sick, ne?¹⁷ And then I heard and saw people on TV, saw people in newspaper who are dyeing of AIDS and then I was scared that maybe to happen to me and then I started to ... to take my treatment.

In Tisha's case, physical health alone was not enough to motivate her towards taking treatment for HIV, but when her physical appearance was called into play, she says she was more willing to take the risk.

¹⁷ Here, "ne?" means, "you know?"

Elaine also talks about her fear of looking like “the people on TV.” Elaine admits that sometimes she questions whether she really is HIV positive because she does not resemble the images of AIDS in the media:

Sometimes I feel in my mind, “Are you really HIV positive?” Because I feel like a ... if I see the people on TV... then I say to myself, “Ohhh, are you going to look like that?”.... And they say it put sores on their mouth and tongue and all that. And I thought to myself, “Elaine, you never had that stuff. The only thing you got is shingles, but you never had sores in your mouth.” Something like that. They say it’s a death penalty.

Perhaps because of this “AIDS as a death penalty” discourse or image perpetuated in the media, women talk frequently of how they appear since their diagnosis and in relationship to the images they see of other people living with HIV in the media.

The media has made HIV into a shocking visual by which people may be scared into getting tested or for their own revenue in the sensationalisation of the pandemic. Either way, these visuals are ones of peoples’ bodies. A woman’s body is something that has been made into an object that can be identified as beautiful or ugly, fat or thin, normal or abnormal, acceptable or unacceptable, white or black, and healthy or unhealthy. In the context of South Africa, where food is scarce and many of the women interviewed speak frequently of food or lack thereof, body weight and appearance take on an added dimension. With the knowledge of their positive HIV status, the women I spoke to suddenly became very aware of weight fluctuations i.e. “Am I too thin?” and “Do I look like I have AIDS now?” And the very drugs that can help people living with the virus, physically, are medicines that alter the body in other ways that may or may not make their HIV status more visible.

At one point in the interview Elaine explains why she finally decided to take

ARVs:

Yes and through the dingis¹⁸ of God that I'm still ... and through the ARVs that I'm using that keep me going. Cause I was very, very thin. I was so afraid to go out of the house. I was thin, thin, thin. And then afterwards when I go on the ARVs. The doctor asked me do I want to go on the ARVs. I'm now on these ARVs for three years. Now the doctor asked me, "Do you want to go on ARVs?" I said, "Yes doctor."

In the above excerpt, Elaine explains that because she was, "very, very thin," she felt compelled to commence ARV therapy. The word "thin" connotes appearance and it is in fact the only physical issue she points to as the driving force behind the commencement of ARV therapy. Perhaps Elaine is suggesting she started the treatment solely because of her appearance.

Linda also talks about how her worries of losing weight and the thin appearance of her body that is a result of stress. She had been staying with her sister and brother-in-law until he became abusive and chased her out. Here she talks about a discussion she had with her employer and how the eviction made her feel:

... it really makes me feel very down you know. And I lose a lot of weight because I was stressing. Yeah. So, they were so worried and so just tell me, "You know that you don't ... you shouldn't be stressed." I said, "How can I control the stress? I can't control the stress." So, now I lose weight.

In fact, Linda's employers also seem to be becoming obsessed with monitoring the appearance of her body and weight. Linda claims to feel both appreciative of this and

¹⁸ The Afrikaans word "dingis" directly translates into "thing" in English. Here, it means "through the grace of God."

annoyed at the same time. In this part of the interview, she talks about a conversation she had with her employer where he is taking about her weight:

“You must try and eat this. If you want your weight.” So everyday they say to me maybe once or twice ... there is a scale [laughing] ... they showed me how to work the scale ... they said, “We’ll monitor your weight now [laughing].” They said, “Yeah, we’ll take care of you,” you know? I said

“Yeah ... I appreciate it but ...” sometimes they can talk things that makes me feel stressed out, you know? Sometimes said I think, “If I could go—leave them ...”

It appears that on one hand, Linda struggles to maintain a particular weight that she finds suitable for her health as well as her appearance. But on the other hand, the constant monitoring of her weight by her self and her employers seems to be an intrusion and an added source of anxiety as well.

Priscilla also has disturbing thoughts about her body because she feels she is getting thinner. She explains that she is not able to find work and this leaves her with too much time to think about the fact that she is HIV positive: “If my mind just flows ... I’m just, ‘Oh, I’m HIV ... I’m so thin.’ My pants, my panties all fall. So that’s why I must go look for something that keep me busy, Anna.” It is significant that Priscilla explains that if her mind is not occupied, she first thinks of her positive HIV status and only second to that worry is her body image being, “so thin.”

She speaks again about compliments that she received that she can no longer accept because of how she now sees herself as an embodiment of the HI virus.

When I go to my brother in (another neighbourhood), then his friends would always tell me, “You look beautiful! Still young!” You know—so. “You would

never say you got four kids.” And I feel so proud, I can’t believe it. Honestly. Then, I ask them,

“Really?”

“You are sexy. Yo! You got four kids, your eldest daughter is 15 ... You look nice after you.” I can’t believe it because I didn’t think that of myself. When I look in the mirror, then I told myself,

“You’re not that Priscilla anymore ...” You know? That is what I said.

But I musn’t do that to myself. I musn’t. Every morning when I look in the mirror, I must always say, “Thank you God ... beautiful girl and ...” You know? But to tell the truth, Anna, that is [not] what I think of myself. I’m not that person anymore and I don’t look cute or whatever.

In the above excerpt, Priscilla says that she is not the same person “anymore.”

Priscilla may be suggesting that because of her perception of her own appearance since her HIV test, even though others see her differently, she may have internalised her negative feelings. Maybe Priscilla has not changed on the outside, rather her mind has changed. She may be expressing the punitive effects of internalised HIV stigma.

Priscilla also talks about changes she sees in her skin. She says the changes have taken place over the last few weeks:

Anna, I know myself, I know my body, I know my skin. You know? This is still the second week that I see my hands is not the same. My skin, it looks darker and my face is also getting darker, because my sister told me, “Oh, your skin is getting black now and a lot of pimples coming on your face.” So I told her,

“Ohh, well ... I’m getting old now.” But you know, it’s the second week that I see my hands. My hands are very thin and my skin is not the same. It feels so ... I cannot even tell you, but my skin looks like a tortoise. My skin looks like that. Honestly. You cannot see it, Anna, because you will not understand, you will not know ... you know but I know my skin, I know myself. It’s totally different.

In the above excerpt, Priscilla speaks again of her appearance in how her hands and skin are, “not the same,” in fact they are “totally different.” She uses this kind of language throughout her descriptions of the visible physical changes she believes have

take place since testing positive. She again suggests that there have been drastic changes in her appearance since her HIV test. In addition, her partner also talks about the appearance of Priscilla as it relates to HIV. Here she relays an argument she frequently has with her partner about how he became infected and subsequently infected her:

So, Anna, he told me, "Before I came to you," he did have someone but not a steady girlfriend, just a 'hit-and-run.' So he told me, "Maybe Priscilla, she gave it to me." That was his words to me. But out of the blue he told me, "No, it cannot be she, because she's fat. And this illness is something that makes you thin." He told me, "You are thin Priscilla, but she is fat. No, I don't think she gave it to me." So, I don't know, Anna. For me, it is so confused, you know?

Because Priscilla has tested positive for HIV, she and her partner have become hyper-aware of her appearance in comparison to other perceived 'healthy' people. The hyper-awareness is reflected in her language too--"it's not the same," "you cannot see it," "its totally different." Because Priscilla believes she has only been living with the virus for one or two years and she claims to have a relatively high CD4 count, it is not clear if her weight loss and skin changes are due to the physiological effects of the virus or her psychological decline. Still she sees her appearance as a measure of her health in regards to HIV. This is problematic because today, the experience of HIV is immersed in a context that sets impossible standards for bodies, beauty, and normalcy for women. To be beautiful and normal means that one does not appear to be living with HIV.

Another area related to how the women I interviewed claim to feel and speak about their body and appearance is talk related to ARVs. Some women talk about how ARVs have made them gain weight and look less like a person who is ill, other women talk about the negative effects the ARVs have had on their appearance, and finally there

is talk surrounding their fear of commencing ARV treatment because of what they have seen and heard happens to one's body as a result of the medicine.

Linda has a lot to say about the effect of ARVs on a person's body. Here she speaks about a woman who was previously in the support group whose body changed when she began talking ARVs:

... there was another lady ... she's no longer in the group. She was thin like me. Pfew!! The day she come, she was bigger than you. The hips! Especially the hips, as if somebody put these steaks on the side here. But here [touching waste] she was so thin. She was ... Pfew, she was beautiful!

Linda also talks about how her own appearance has gone through changes she says are caused by ARVs. Here she talks about some of the negative side-effects:

I didn't have those other bad side effects that cause me to sleep in hospital like other—other people they will get admitted. The only thing that I did have--it loses your shaping ... becoming ... you lose your shape. If you like this [hourglass gesture], you see you've got a figure and hips and that. You coming other thing, you know? Your bums becoming ... if you did have big bums—they getting ... they dropping! ... Yes!! They dropping down [laughing]. And then you've got your ... your boobs ... becoming big--you're becoming shapeless!! I was worried about that [laughing]!! I just complained about that. Because they ask you, "What do you feel now?" I said,

"I'm feeling ..." Because if they check me,

"You healthy! So what is wrong?" I said no. Because also I did lose weight about that problem and I told them ... they said, "Yeah but you're healthy! You're not sick ... the important thing it that you're not sick."

In the above excerpts, Linda seems to be saying that ARVs may improve one's appearance, but in her case, the body-shape changes she experienced were not what she would consider an improvement. Linda relays her discussion with her children and her

doctor about how her initial body shape change as a side-effect of the ARVs has caused her to actually lose weight again because of the stress from it. Now, the doctors, her children, and she herself are trying to convince her that her body shape is now coming back to 'normal' and that the important thing is that she is physically healthy:

So all the time now when I'm wearing, I can feel myself now. If I am walking, I can feel myself now—I am better. So, I said to my children, "How do I look?"

They say, "Mom you fine now. Now you good."

I say, "Really?"

They say, "Yeah, it's not like that time."

I say, "Ok [laughing]." ... I don't know why ... and if you complain to the doctor they say,

"We can't do anything, because, yes they do this ... it's other side effects or other ... they do that shapeless, but as long as you stay alive. It's what we most worried about ..."

Although Linda says her health is her primary concern, she speaks at length about the negative changes she has seen in her appearance. 'Health' is what she and her doctors seem to be striving for, but as Linda has said, her appearance has causes her to lose weight at times—which is indeed, an affect on her health. Fortunately, in the above excerpt, Linda seems to be coming to terms with her changed body and perhaps she has convinced herself that worrying about her weight and body shape are not what she should focus on.

Priscilla, who is not on ARVs, has mentioned several reasons for not commencing ARV treatment. One reason is the ongoing problem in South Africa regarding the choice that people living with HIV must make between receiving social disability grants or receiving ARVs (Hardy & Richter, 2006). Priscilla has mentioned that she needs the social disability grant that she may be eligible for when her CD4 count is low enough that

the government recognises her as disabled. She is aware that the chances for receiving a grant will be diminished if she goes on medication. In addition, Priscilla says she is also concerned with commencing ARV treatment because of the physical effects they have on a person's appearance:

I did tell you the truth ... I don't think, like I see for myself ... I see a lot of pills, medicine ... it gives you side effects if you use it and I'm scared to go on treatment like that. You know like the doctor, he told me it's very good for umm ... the ARVs—he said that is a very good drug or whatever, but he told me it is very good ... I did hear a lot what the people say it can give you side effects. You know, I did see side effects. You know, it's not nice on your legs, arms and you know how's the people ... But I don't know, Anna, like I told you, I'm very scared about ARVs because I read a lot about ARVs and I did see what did ARVs do to people because people did tell me—this is what ARVs do. I'm really scared. To tell you the truth, I'm really scared.

So the choices, as they relate to ARVs, are not simply between sickness and health. Not only must women living with HIV choose between ARVs and social disability grants, they have a more complex decision to make. Women must also consider that their physical 'beauty' may be at stake.

Clearly the women interviewed have a variety of concerns with their bodies and their appearance. Kirk and Okazawa-Rey (2004) explain that our bodies, "provide us with a living, physical basis for our identity" (p. 111), either as an individual or as a community. Specifically, the human body is the primary site for the physical enactment of the constructs of gender (Reischer & Koo, 2004). Reischer and Koo (2004) in their review of the theoretical orientations of the body in research, find that the body as a "symbol" and as an "agent" emerges in the literature (p. 297). The idea that the body is an agent, or as a tool with which a goal can be accomplished, is evident in the ways in

which women must use their bodies and appearance as agents in society. Women in particular have a special burden placed on them concerning their bodies. How a woman sees herself as well as how others see her and how she believes others see her are major issues for women in a world in which they are expected to conform to hegemonic standards of beauty if they want to gain acceptance and avoid stigma and further marginalisation.

The standards set today for bodies, beauty, and normalcy for women are frequently impossible to achieve even if one is what society considers a 'healthy' person. In fact, according to Persson (2005), what she refers to as the "AIDS body" has been constructed as "ugly," "different," and immoral (p. 245). South African women are conscious of their bodies in comparison to beauty norms and an element of the standard is that they do not appear to be HIV positive (Hoosen & Collins, 2004). For the women in the present study, there is virtually no place for the bodies and appearances of women living with HIV. The women I spoke to are all (with the exception of one woman) living in extreme poverty. Most women either live in public housing or in shacks built on the sand of townships. In some neighbourhoods there is no electricity or plumbing. People use outhouses, which are unsanitary and often close to the shacks and they have to walk to a cold water pump to get water each day for cooking and washing over a wood fire from fuel gathered on the roadside. These same women talk of struggling to find food each day and they often have to go door to door and collect small amounts of food from the people in their neighbourhood until they have enough for a small meal for the family. Despite the pressures of these life and death struggles including the problem of living

with HIV, the women I interviewed struggle with their appearances and what they see as their 'fading beauty.'

4.5 Summary: Discourses of Femininity and Normalisation

Through discourses of work and relationships with men, the imperative of disclosure, doing care work for men and children who may be abusive, and body image considerations, the women interviewed draw upon an overarching discourse of femininity. The women emphasise their need to work, not only as an act of providing for their families and having a sense of purpose in their lives, but also because it is 'normal' and a highly regarded behaviour for some women in South Africa. The discourse of disclosure can also be seen as a pressure for women to 'normalise' in the sense that the disclosure discourse is one that is drawn upon by the medical and HIV activist communities in South Africa as a necessity for people living with HIV. As well, the women underscore the necessity of doing care work for children and men, even though they may be abusive. Care work is a type of work that the patriarchal system pressures or forces women to perform and it is considered a feminine duty. Finally, the discourse of the appearance of their body in all of its changes that may or may not be due to HIV and ARVs emerges as a great concern. The women voice their struggle to conform to Western expectations of beauty as well as non-Western ideals of a healthy body as being 'big.' Adhering to feminine beauty and body ideals is a way for marginalised women to appear as healthy and normal. The emphasised femininity and normalising discourses emerge as tools by which women attempt to bring themselves back from the edge of poverty and HIV. These methods are at times, problematic because they are the very tools

with which the patriarchy maintains the status quo in the oppression of women. However, there are sites of resistance where women are able to use exaggerations of femininity to their advantage and pull themselves back into the normal world.

University of Cape Town

CHAPTER 5: CONCLUSIONS

The present study suggests that women living with HIV face major obstacles in their lives as they struggle against stigma and ‘othering’ forces. The interviews were semi-structured and the questions focused on issues that emerge in the existing literature on gender and HIV. The women, however, directed the conversations toward other issues. The following discourses emerged in women’s talk about their experiences of living with HIV: Allying themselves with men who may or may not be good partners, and work as a way to normalise themselves; deliberating whether or not to disclose one’s status to family and friends as the medical and psychological communities dictate; doing care work for men partners and children while living in abusive situations; and coping with or becoming hyper-aware of body changes that are thought to be brought on as a result of HIV or ARVs.

5.1 Discourses of Normalisation: Work and Men

In this study, two issues, work and men, emerge as tools that women use as ways to normalise themselves. Women speak about work as a way to attempt to meet practical material needs and as well a way of normalising their lives. Under the apartheid regime in South Africa, women of colour, especially in the Western Cape, sometimes had an advantage over men in the labour market because women were given preference over men when seeking employment (Salo, 2005). This placed women in many households in the situation of being the primary bread-winners and bread-winning may have evolved into a behaviour identified with femininity. Although it is now 12 years after the collapse of the apartheid government, the remnants of this connection is still apparent in women

who feel that being a paid worker or bread-winner for their household is an ideal feminine quality.

For these women, working is not only a source of pride and a sign of femininity, but with the status of bread-winner comes power. In South Africa, like the rest of the world, men hold the majority of the money and employment opportunities are low for everyone but even lower for women (Petros et al., 2006). Having access to a way to earn a living and thereby supporting themselves and their households is critical source of subsistence and a basis of power. This is an unusual position to be in given these women were living under a deliberately racist patriarchy and it is a reversal of the oppressive gender hierarchies in which work and talking about work and earning money is in the realm of white masculinity. However, for this particular group of women, talking about and doing work is decidedly feminine.

In the interviews, the women speak frequently of their work lives to perhaps emphasise the fact that they are not only carrying out tasks that make them useful and capable, they are carrying out the normal gendered expectations prescribed for women. They also gain a degree of power in doing so in attempts to de-stigmatise or normalise their 'abnormal' situation of being HIV positive. This process could work in favour of women living with HIV and arguably does so in the case of some of the women interviewed. But this normalisation strategy by which the women emphasise an element of femininity, may not always be to their advantage. As in the study done by Salo (2005) with young women (and men) in Manenberg, a disadvantaged community on the Cape Flats, sometimes renegotiating or emphasising femininity only moves a woman from one oppressive environment or situation to another.

A second factor women identify as important to normalising their lives is their relationships with men. Having monogamous relationships with or being married to men is identified as a way to normalise their lives, but like work, this strategy also has its problems. Marriage is a powerful social institution that is associated with adulthood, responsibility, and 'normal' sexuality. Being married, or in a marriage-like relationship, therefore is a way of presenting oneself to the world as a normal upstanding citizen, but marriage may also be an essential tool for controlling individual women and maintaining a system that oppresses women in general. Some theorists argue that marriage may be the key to maintaining gender inequality in society. In his classical work, Engels (1884/1970) points out that society must have changed in a particular way and at a particular time to produce the oppression of women. Through an elaborate theory, Engels concludes that this oppression stemmed from the construct of marriage which provided a way for men to control their wealth and necessitated their control of women. Engels' theories focus on how wealthy men use marriage in this way. Socialist feminists have developed his ideas theorising that working-class men also use marriage to exert dominance over women, even when the women are working outside the home (Hansen & Philipson, 1990; Kain, 1993). For the women I interviewed, herein lies the danger. On one hand, these women need men as a buffer against stigma. On the one hand, in order to appear normal and in order to have intimate heterosexual partners, they believe they must have a man in their life with whom they maintain a marriage or a marriage-like relationship. However, this strategy may create even more oppressive situations for women when the men are abusive and need care creating an emotional, physical, and economic deficit in the household for which the women are responsible.

The debate in the literature surrounding marriage as a favourable or unfavourable institution is illustrated in the debate surrounding gay marriage. Weston (1991) refers to this debate as assimilation or transformation. The LGBT (lesbian, gay, bisexual, transgendered) community is fighting for the right to marry just as heterosexuals have the 'right' to do. But that leaves the question: Should they be fighting to assimilate or should they fight to transform the institution of marriage into a less oppressive one? The same case could be made for women living with HIV. Rather than fighting to maintain marital relationships (or marriage-like relationships) with men in our lives as a source of normalcy, we should be fighting for a transformation of the system that imposes the gendered stigma and oppression.

5.2 Discourses of Disclosure

The women in this study speak about the ways in which disclosing their HIV status has affected them. Some women have disclosed with good results that allowed them to gain certain forms of social support. But others struggle with disclosing because they have had to endure a great deal of stigmatisation and marginalisation already and they quite literally may not be able to afford a disclosure-gone-wrong. Whatever the consequence of disclosure is for an individual woman, gendered stigma by others is common and powerfully felt and is often even internalised by the woman herself (Fife & Wright, 2000). It needs to be acknowledged that disclosure may help or hinder a situation (Klitzman et al. (2004). Furthermore, the women in the present study who express their anxieties surrounding the people to whom they have not yet disclosed, need to be advised that their decisions to disclose or not are acceptable. Women need to be encouraged and

empowered to be confident in making their own decisions about what they perceive as a safe disclosure. And they need to be assured that leaving the decision up in the air can be a conscious, deliberate, and sometimes the best decision given the circumstances.

Disclosure should be empowering but it requires relinquishing some of the gendered ideologies that women in this situation cling to as their only means of holding together a possible, normal life in the margins of society.

Perhaps the disclosure dilemma should not be posed as strictly a choice between disclosing or not disclosing but instead bringing in a third option, exerting pressure on society and government to do away with the structures that make stigma possible. Stigma, although in all of its multifaceted forms is under-researched, is known to be exacerbated because of raced, classed and gendered hierarchies. Through the process of othering and marginalisation, stigma is made possible. These oppressive processes and forces allow the dominant social structures to place blame on and subsequently stigmatise, discriminate and oppress people whom they have constructed as ‘high risk,’ or ‘virus vectors,’ mostly because of their real status as poor people of colour, especially women. One way these truths can be overcome is indeed through mass disclosure which would lead to greater community acceptance of people living with HIV along with which the uncovering of the truths about who is really to blame and why stigma is possible, will come real social change. The steps towards these kinds of actions have yet to be laid out but one step may be to more rigorously train women living with HIV to disclose in different situations and make women aware of when they should and should not consider disclosing. And most importantly women need to understand the broader impact of these

disclosures on the oppressive forces in society so that they can decide where their personal decisions fit best in their own lives as well as in the larger social context.

5.3 Discourses of Care Work in Violent Situations

The women in this study speak of doing care work for men and children. Care work alone is problematic for a variety of reasons one of which is the fact that the burden of this work is shouldered by women. In fact, it appears that women feel so compelled to do this work because they believe it is expected of them as their feminine duty, that they carry on doing the work for men and children even when the men are abusive, the children are resistant, and the women themselves are in the greatest need of care. Additionally, the fact that men continue to inflict abuse on their partners in myriad ways also indicates that gendered expectations have gone very wrong.

The gendered hegemonic discourses women draw on in speaking of caring for their partners and children indicate the need for the restructuring of the hegemonic structure of femininity as well as masculinity. Although this is a lofty goal, there is a glimmer of hope in that there are now studies such as the one by Boonzaier and de la Rey (2004) in which men as well as women are involved in the exploration of violence against women. On a grassroots level, there is talk, in the international HIV activist community as well as HIV support groups in Cape Town, of directing support towards couples so that support regarding issues such as care work and abuse are directed towards perpetrators as well as the survivors of abuse. These types of strategies are hopeful because despite the relatively more powerful position in which men are placed in comparison to women, the men, as well as the women in the community in which the interviews took place, are marginalised

because of their socioeconomic status. As more people become infected with HIV and converge in support groups there are more instances in which men as well as women can learn about where violence stems from. It will become more and more apparent that when one is poor and marginalised from the rest of the world because of race, nationality, and HIV status, reacting against the power structures makes more sense than oppressing a woman partner.

5.4 Discourses of Women's Bodies

In this study women speak about the appearance of their bodies including how their bodies have changed shape or have become thinner as well as the ways in which they believe their beauty has faded. There seems to be no spaces for women living with HIV, in a world greatly influenced by exploitative and oppressive beauty and body standards. The even larger problem remains that the women must exert precious resources and energy on the issue of the appearance of their bodies in order maintain relationships with men as well as to avoid being further marginalised. In fact, women must often visibly display their femininity (which is embodied in the set of ideals set forth by the dominant culture) in order to compensate for any of their 'unfeminine' characteristics (Rodin, 1993). This could include bodies effected by poverty and HIV. According to Kirk and Okazawa-Rey (2004) forcing women to be preoccupied by their appearance is an effective way of oppressing women and maintaining the patriarchal system. Furthermore, it endangers women who may need body-shape-changing ARVs, but who must also adhere to impossible beauty standards.

On a more hopeful note, according to Reischer and Koo (2004), because the bodies of women are the site of oppression, they may also be the site of empowerment. Persson (2005) identifies a resistance against the stigma and exclusion brought on by the visible side-effects of ARVs in communities of gay men in Australia. The men in the Persson study have exhibited, “a kind of defiant ‘normalisation’ of HIV” (p. 250) in that they are creating a sense of “brotherhood” in being comfortable and open about their own body-shape changes. However, the resistance exemplified in the Persson study is achieved by men. The body then, can be a site of successful resistance, albeit within the patriarchal power structure. However, there are women like Elaine, who are actively resisting the necessity to adhere to a certain set of standards that excludes the bodies of women living with HIV. Towards the end of the interview, Elaine explains how she is becoming more proud to be an HIV positive activist and beginning to feel better in her own thin and powerful body:

Like the lady who said to me when I got that blue sweater [t-shirt] on at that December the 1st¹⁹—last year.

“Oh this is a shit sweater! Why you have to put on that sweater?!” I said to her,

“You know what? You don’t know what you’re talking, because why, this sweater I represent all the people living with HIV.” I said to her, “You don’t know. I represent the people living with HIV and those who have passed away with HIV.” I said, “That’s why I’m wearing this today and it makes me look beautiful. Why you come and tell me this is stupid nonsense shit? It’s not that. You don’t know what you talking about!” No I know how to...I don’t know if because I went to the support group or I learned about HIV. Now I’m like nobody’s gonna tell me—I’ve got an answer for everybody.

¹⁹ December 1st is World AIDS Day and Elaine is speaking about wearing a t-shirt that proclaims her HIV status in commemoration of this day.

5.5 Theoretical and Methodological Implications

These discourses around work and men, disclosure, care work, and body images reflect the concerns women have with being pushed to the very edge of society because of race, poverty, and HIV. This marginalisation necessitates women draw themselves back into the realm of acceptance and normalcy for their own survival and well-being. This 'coming back to normal' requires women emphasise certain feminine behaviours that tell society that they are not 'HIV,' but rather, they are 'normal women.' These ideas, although they are in some ways related to issues in the literature on gender and HIV, have not been widely researched.

The predominant scientific and academic discourses on gender and HIV emerge from the West. Those discourses have significant effects on the ways in which the virus and the people living with it are treated globally. This becomes problematic when attempting to understand women in the global South, specifically South Africa, where so many women have been infected and affected by the virus. Furthermore, the literature tells a story from the point of view of scholars and what scholars think should be done about the HIV 'problem.' Western scholars have dominated the protocols for both the development of tools used to prevent HIV infection as well as the ideas and practices that deal with the people who have already been infected (as well, they have monopolised the resources with which to implement these protocols). There is an overarching belief reflected in scholarly work that knowledge is the single factor in 'combating HIV'. For example, in HIV support groups all over the world, including South Africa, it is common procedure to hold workshops for members about using condoms, healthy cooking, and personal hygiene. The good news is that some programmes in the South as well as the

West have shown promise and do empower people to take care of themselves on several different levels. The statistics, however, show that HIV prevalence and infection rates in most parts of the world are not decreasing or slowing down significantly and are in fact rising for women. For this reason, among others, it will be important to push for a shift in the research surrounding HIV. In this regard, a feminist approach might hold promise.

According to Mies (1983), one of the principles of feminist research is to replace the voices of the power structures with the voices of people who have been invisible or marginalised. In the world of academia we have established a huge body of literature from “above” and now because of the continuing escalation of HIV, it appears that we need a rather new approach which is the approach from “below” (Mies, 1983, p. 120). The discourses that draw on femininity and normalisation in the present study depart significantly from the dominant ways in which HIV has been understood and theorised. What is interesting about this is that not only does gender play a role in women’s experiences regarding their risk of becoming infected and the subsequent specific difficulties they may face in dealing with HIV infection as it is discussed in the literature, but that gender also emerges in different ways as a critical issue from the point of view of the women. The women in this study seem to perceive their contracting and living with HIV as amounting to a departure from the hegemonic norms of gender, femininity in particular. As a result, they draw on discourses of exaggerated femininity as a way to compensate for their lack of conformity to particular gendered expectations. However the way in which the women in this study have dealt with certain aspects of HIV is ironic. They have relied heavily on a discourse of resistance against the hegemonic ideas about HIV that are reproduced in the West and that are not as relevant to themselves as the

literature would claim. Instead, women are forced to rely on the exaggeration of specific feminine gender expectations. Goffman (1988, p. 6) asserts that through “gender displays,” we learn to convey our gender to others such that our gendered behaviours appear to be natural. Connell (1987; cited in Jackson, 2001) uses the term “emphasised femininity” to describe femininity that is characterised by displays of nurturance and selflessness. The women in the present study seem to exaggerate their femininity in specific ways in their frequent talk of what they consider feminine behaviours and expectations such as working, being in monogamous relationships with men, doing care work, and worrying about their appearance. Exaggerated femininity is a dangerous tool in this case as it locks women into roles and behaviours that could become ultimately detrimental. For example, as we already know many HIV prevention and care programmes encourage women to shoulder the burden of the care and responsibility in their community in dealing with HIV and other issues because patriarchal ideals expects women to do this kind of work. Exaggerated femininity in this case may not be in the best interest of women whose own health needs are ignored or threatened because of the care work burden.

However, the women are also challenging power structures and dominant discourses by calling for fewer workshops on how to use condoms and dress bed-sores and more for change at the level of the community. They are calling for a community that is supportive of human rights and women regardless of their HIV status. Furthermore, they describe a community that recognises women living with HIV as normal people who are trying to live life and who happen to be living with a common disease. This is not to say that the women interviewed have perfect lives except for the fact that they are living

with HIV. In fact, all of the women interviewed have very difficult lives as they struggle to support themselves and their children and partners with few resources and little to no money. These difficulties highlight broader issues of poverty and marginalisation as they affect the lives of women living with the virus.

Women's discourses on their lives expose the error of accepting a single story or plan of action to deal with HIV. No one can live in community that supports the idea of human rights if none of the people can find jobs or food for their families. In other words, it is necessary that people living with HIV have not only knowledge or a supportive community, but that they are able to take care of their basic physical needs. Just as Lees (2006, October) found in his HIV research and activism internationally, the dominant globalised story of HIV obscures real issues and complexities surrounding the virus. The findings of the present research, highlight the fact that issues surrounding poverty, gender, and marginalisation have an impact on women's experiences of living with the virus. The HIV story and plan as it exists today is not effective in light of the fact that HIV is a social problem that is inextricably linked to marginalising and oppressive conditions. These findings have implications for policy and practice in that more comprehensive and adaptive strategies that focus on human rights and social problems need to be put into place to for the women in this particular community and for people living with HIV worldwide.

5.6 Recommendations for Practice and Policy

5.6.1 Gender Mainstreaming in HIV

Researchers and activists alike could ask the question, “What about HIV does *not* relate to women and what social sectors are *not* affected by HIV?” They could also ask, “What aspects of HIV are not shaped by gender?” In speaking about their lives, the women in this study, point to the organisation of gender in several social milieus--paid work, marriage, care work, and ideals of beauty as critical to their experience with HIV. Despite the fact that poor people and women are increasingly vulnerable to HIV and the virus has spread into all social sectors and the infrastructures of many countries, and that gender and HIV are strongly connected, HIV is still predominantly viewed as a bio-medical problem (Eelsey, Tolhurst & Theobald, 2005). The issues of gender and HIV are still viewed as separate areas of concern and they are detached from other sectors (Tiessen, 2005). One possible way to tie the issues together in our thinking and in our policy making is gender mainstreaming. The idea of gender mainstreaming as a way to address many social issues came to light in 1995 with the adoption of the Beijing Platform for Action at the UN International Conference on Women. According to Eelsey et al. (2005), gender mainstreaming, “therefore aims to ensure that women’s, as well as men’s concerns and priorities influence the ‘mainstream’ activities of development, including resource allocation, policy and legislation formulation, and programme or project planning, implementation, monitoring and evaluation” (p. 991). When HIV is added to the equation, it means that the effects of the virus have to be taken into consideration in these same ways.

Gender mainstreaming in HIV is just beginning to emerge as a strategy to uphold human rights that could be more successful than the current strategies to eliminate the spread of the virus and support those people living with HIV. Gender mainstreaming efforts have begun, for example, in sub-Saharan Africa. But these efforts, however, have not been without problems. Unfortunately gender mainstreaming regarding HIV has been misinterpreted by governments and policy makers who believe that by adding more women to the predetermined structures in government, business, and other social sectors, gender mainstreaming and subsequently HIV mainstreaming has taken place (Tiessen, 2005; True, 2003). Increasing the numbers of women receiving social support and ARVs is a positive step; however it does not address or get at the root of the problem of HIV. Gender mainstreaming in HIV is much more than adding women and stirring. Gender mainstreaming in HIV aims to fundamentally change the way that governments and social sectors are structured. It seeks to, “reinvent processes of policy formulation and implementation across all issue areas at all levels from a gender-differentiated perspective...” (True, 2003, p. 369). It must be recognised that HIV is a social problem and the gender norms that currently put women at disadvantaged positions must be overturned if HIV is to be eliminated and treated properly.

Gender mainstreaming in HIV might be a productive way forward but before it can be successful, it has to take into consideration exactly what changes need to take place. Unfortunately, the body of literature on HIV is not focused on the virus as a social problem. Many studies involve more men than women and then generalise their conclusions. Alternatively, ‘women’s issues’ are addressed in a way which further stigmatises women living with the virus. There are few studies that allow women living

with HIV to voice their concerns about HIV and about their lives holistically. There is also the problem of HIV research painting women as victims (Oinas & Jungar, 2005, January), and not adequately highlighting the ways in which women are able to resist this victim status and offer themselves and other women positions of power. However there are increasingly more women activists living with HIV, like the women in the International Community of Women Living with HIV/AIDS (ICW), speaking up about the concerns and experiences of HIV-positive women (Bell, 2005). The women in the ICW point out that laws, programmes and policies are, “often determined by people who do not understand the realities in which HIV-positive women live their lives” (Bell, 2005, p. 71). In addition, Seidel (1993) argues that the activist discourse is one in which African researchers’ and professionals’ voices need to be heard in the international HIV arena. Bell’s (2005) paper goes further and calls for the need to hear the voices of women in determining the, “direction of policies and programmes” (p. 71).

It is the aim of the current study to present empirical evidence to convey the real priorities and concerns of women living with HIV in contribution to the needed body of literature surrounding HIV as a gendered social problem. This research and further research along the same lines, must be utilised in the creation and restructuring of future policy and programmes for women as well as men living with HIV. Most importantly, the process as well as the findings of this study and studies like it, are ways for women who have been marginalised to be empowered and to demand their voices be heard.

5.6 Study Limitations and Further Research

This study was limited to one support group servicing a particular neighbourhood in Cape Town, South Africa. Exploring the same area of interest in other neighbourhoods in Cape Town as well as support groups on a national level would add to the comprehensiveness of the data. Additionally there are support groups locally and internationally that are employing gender mainstreaming strategies and working with women living with HIV and their partners in hopes of overturning some of the oppressive gender hierarchies for the benefit of men as well as women. Evaluating the effectiveness of such programmes would be of value to women living with HIV in that this type of support is so greatly needed. In fact, the women in this study have very little support and there is a call for practical support regarding their need for advocacy when applying for social disability grants, transportation for disabled people attending clinics regularly, ways of subsidising school fees for children, and understanding the effects of and accessing ARVs.

Most importantly, research such as the present study needs to be conducted on an international level, because it is not as if HIV is a problem confined to southern Africa. HIV is a global problem and although the purpose of qualitative research is to examine an idea in all of its complexities, the importance of this research and research like it is that it indicates that things are not always as they seem (or what the dominant power structures would like us to believe). The present study indicates that women's experiences of living with HIV are highly gendered and their concerns reflect much more complex issues than those reflected in the dominant bio-medical discourses of HIV. Although women globally may not draw on the same discourses as the women in the present study, women world-

wide may also be experiencing and speaking about HIV in ways that differ from the dominant discourses. HIV is not going away, it is in fact an ever-growing problem which means it needs to be addressed in new ways if we are to successfully live with and live without HIV.

University of Cape Town

REFERENCES

- Adam, B. & Sears, A. (1996). *Experiencing HIV: Personal, family and work relationships*. New York: Columbia University Press.
- Ashton, E., Vosvick, M., Chesney, M., Gore-Felton, C., Koopman, C., O'Shea, K., Maldonado, J., Bachmann, M., Israelski, D., Flamm, J. & Spiegel, G. (2005). Social support and maladaptive coping as predictors of change in physical health symptoms among persons living with HIV/AIDS. *AIDS Patient Care and STDs*, 9, 587-598.
- Austin, S.B. (1989- 1990, winter). AIDS and Africa: United States media and racist fantasy. *Cultural Critique*, 14, 129-152.
- Bakken, S., Holzemer, W. L., Brown, M. A., Powell-Cope, G. M., Turner, J. G., Inouye, J., Nokes, K.M. & Corless, I.B. (2000). Relationships between perception of engagement with health care provider and demographic characteristics, health status, and adherence to therapeutic regimens in persons with HIV/AIDS. *AIDS Patient Care and STDs*, 14, 189-197.
- Bell, E. (2005). Advocacy training by the international community of women living with HIV/AIDS. *Gender and Development*, 13, 70-79.
- Boonzaier, F. (2001). *Woman abuse: Exploring women's narratives of violence and resistance in Mitchell's Plain*. Master's thesis. University of Cape Town, Cape Town, South Africa.
- Boonzaier, F. (2005). Women abuse in South Africa: A brief contextual analysis. *Feminism & Psychology*, 15, 99-103.
- Boonzaier, F & de la Rey, C. (2004). Woman abuse: The construction of gender in women and men's narratives of violence. *South African Journal of Psychology*, 34, 443-463.
- Boonzaier, F. & Shefer, T. (2006). Gendered research. In T. Shefer, F. Boonzaier & P. Kiguwa (Eds.), *The gender of psychology* (pp. 3-11), Cape Town: University of Cape Town Press.
- Bordo, S. (1993). *Unbearable weight: Feminism, western culture, and the body*. Berkeley: University of California Press.
- Brief, D.J., Bollinger, A.R., Vielhauer, M.J., Berger-Greenstein, J.A., Morgan, E.E., Brady, S.M., Buondonno, L.M. & Keane, T.M. (2004). Understanding the interface of HIV, trauma, post-traumatic stress disorder, and substance use and its implications for health outcomes. *AIDS Care*, 16, 97-121.
- Castle, S. (2004). Rural Children's attitudes to people with HIV/AIDS in Mali: The causes of stigma. *Culture, Health & Sexuality*, 6, 1-18.

- Catz, S. L., Heckman, T. G., Kochman, A. & DiMarco, M. (2001). Rates and correlates of HIV treatment adherence among late middle-aged and older adults living with HIV disease. *Psychology of Health and Medicine*, 6, 47-58.
- Chacham, A.S., Maia, M.B., Greco, M., Silva, A.P. & Greco, D.B. (2007). Autonomy and susceptibility to HIV/AIDS among young women living in a slum in Belo Horizonte, Brazil. *AIDS Care*, 19, S12-S22.
- Chesney, M. A. (2003). Adherence to HAART regimens. *AIDS Patient Care and STDS*, 17, 169-177.
- Chirimuuta, R. & Chirimuuta, R. (1989). *AIDS, Africa and racism*. London: Free Association Books.
- Collins, E.J., Burgoyne, R.W., Wagner, C.A., Abbey, S.E., Halman, M.H., Nur, M.L., Walmsley, S.L. (2006). Lipodystrophy severity does not contribute to HAART nonadherence. *AIDS and Behavior*, 10, 273-277.
- Collins, P.H. (2000). *Black feminist thought: Knowledge, consciousness and the politics of empowerment*. New York: Routledge.
- Connell, R.W. (1987). *Gender and power: Society, the person and sexual politics*. Cambridge: Polity Press.
- Deacon, H., Stephney, I. & Prosalendis, S. (2005). *Understanding HIV/AIDS stigma: A theoretical and methodological analysis*. Cape Town: Human Sciences Research Council Research Monograph.
- Delahanty, D.L., Bogart, L.M & Figler, J.L. (2004). Post-traumatic stress disorder symptoms, salivary cortisol, medication adherence, and CD4 levels in HIV-positive individuals. *AIDS Care*, 16, 247-261.
- Department of Labour Employment Equity Act, Act No.55, Republic of South Africa (1998). *Code of good practice on key aspects of HIV/AIDS and employment*. Retrieved on August 3, 2007, from <http://www.labour.gov.za/download/10141/Code%20of%20Good%20Practice%20on%20the%20Key%20Aspects%20of%20HIV%20and%20AIDS%20and%20employment.doc>.
- Department of Social Development, Republic of South Africa (2006). *Report on incentive structures of social assistance grants in South Africa*. Retrieved on August 3, 2007, from <http://www.socdev.gov.za/documents/2006/incent.doc>
- Derlega, V.J., Winstead, B.A., Greene, K., Serovich, J. & Elwood, W.N. (2002). Perceived HIV-related stigma and HIV disclosure to relationship partners after finding out about the seropositive diagnosis. *Journal of Health Psychology*, 7, 415-432.

- DeVault, M.L. (1996). Talking back to sociology: Distinctive contributions of feminist methodology. *Annual Review of Sociology*, 22, 29-50.
- De Vault, M.L. (1999) *Liberating method. Feminism and social research*. Philadelphia: Temple University Press.
- Dilley, P., (2004). Interviews and the philosophy of qualitative research. *The Journal of Higher Education*, 75.1, 127-132.
- Dobash, R.E. & Dobash, R.P. (1979). *Violence against wives. A case against patriarchy*. New York: The Free Press.
- Doyal, L. & Anderson, J. (2006). HIV-positive African women surviving in London: Report of a qualitative study. *Gender & Development*, 14, 95-104.
- Dunkle, K.L., Jewkes, R.K., Brown, H.C., Gray, G.E., McIntyre J.A. & Harlow, S.D. (2004). Transactional sex among women in Soweto, South Africa: Prevalence, risk factors and association with HIV infection. *Social Science & Medicine*, 59, 1581-1592.
- Durrheim, K. & Wassenaar, D. (1999). Putting design onto practice: Writing and evaluating research proposals. In M. Terre Blanche & K. Durrheim (Eds.), *Research in practice: Applied methods for the social sciences* (pp. 54-71). Cape Town: University of Cape Town Press.
- Elsay, H., Tolhurst, R. & Theobald, S. (2005). Mainstreaming HIV/AIDS in development sectors: Have we learnt the lessons from gender mainstreaming? *AIDS Care*, 17, 988-998.
- Engels, F. (1884/1970). *Origins of the family, private property and the state*. New York: International Publishers.
- Farmer, P. (1992). *AIDS and accusations: Haiti and the geography of blame*. Berkeley: University of California Press.
- Fife, B.L. & Wright, E.R. (2000). The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer. *Journal of Health and Social Behavior*, 41, 50-67.
- Flick, U. (2006). *An introduction to qualitative research* (3rd ed.). London: Sage.
- Folkman, S., Chesney, M. & Christopher-Richards, A. (1994). Stress and coping in caregiving partners of men with AIDS. *Psychiatric Clinic of North America*, 1, 35-53.
- Foucault, M. (1978). *The history of sexuality: An introduction* (Vol.1). New York: Vintage

- Foucault, M. (1980). *Power/knowledge: Selected interviews and other writings, 1972-1977*. New York: Pantheon.
- Friedland, J., Renwick, R. & McColl, M. (1996). Coping and social support as determinants of quality of life in HIV/AIDS. *AIDS Care*, 8, 15-31.
- Gallo, R.C. (2006). A reflection of HIV/AIDS research after 25 years. *Retrovirology*, 3, 1-7.
- Gavey, N. (1989). Feminist poststructuralism and discourse analysis: Contributions to feminist psychology. *Psychology of Women Quarterly*, 13, 459-475.
- Goffman, E. (1963). *Stigma: Notes on the management of a spoiled identity*. Englewood Cliffs, NJ: Prentice Hall.
- Goffman, E. (1988). *Gender advertisements* (Rev. ed.). New York: Harper.
- Green, G., (1993). Editorial review: Support and HIV. *AIDS Care*, 5, 87-103.
- Guedes, A. (2004). Addressing gender-based violence from the reproductive health/HIV sector, a literature review and analysis. *United States Agency for International Development (USAID)*.
- Gunsallus, J.A. (2006). The "Condom Lady" speaks: Female sexuality discourses and HIV prevention in community-based organisations (Doctoral dissertation, State University of New York at Albany, 2006). *Dissertation Abstracts International*, 67/01, 350.
- Hader, S.L., Smith, D.K., Moore, J.S. & Holmberg, S.D. (2001). HIV infection in women in the United States. Status at the millennium. *Journal of the American Medical Association*, 285, 1186-1192.
- Hallman, K. (2005). Gendered socioeconomic conditions and HIV risk behaviours among young people in South Africa. *African Journal of AIDS Research*, 4 37-50.
- Hansen, K., Philipson, I. Eds. (1990). *Women, class and the feminist imagination: A socialist-feminist reader*. Philadelphia: Temple University Press.
- Hardy, C. & Richter, M. (2006). Disability grants or antiretrovirals? A quandary for people with HIV/AIDS in South Africa. *African Journal of AIDS Research*, 5, 85-96.
- Harrington, S. (1997). Women and AIDS: Bodily representations, political repercussions. In D.S. Wilson & C.M. Laennec (Eds.), *Bodily Discursions, Genders, Representations, Technologies* (201-219). Albany: State University of New York Press.
- Hollway, W. (1983). Heterosexual sex: Power and desire for the other. In S. Cartledge & J. Ryan (Eds.), *Sex and love: New thoughts on old contradictions*, (pp. 124-140). London: Women's Press.

- Hoosen, S. & Collins, A. (2004). Sex, sexuality and sickness: Discourses of gender and HIV/AIDS among KwaZulu-Natal women. *South African Journal of Psychology*, 34, 487-505.
- Huff, J.L. (2001). A 'horror of corpulence': Interrogating Bantingism and mid-nineteenth-century fat phobia. In J.E. Braziel & K. LeBesco (Eds.), *Bodies out of bounds: Fatness and transgression* (pp. 39-59). Berkeley: University of California Press.
- Issiaka, S., Cartoux, M., Ky-Zerbo, O., Tiendrebeogo, S., Meda, N., Dabis, F. & Van de Perre, P. (2001). Living with HIV: Women's experience in Burkina Faso, West Africa. *AIDS Care*, 13, 20-29.
- Jackson, S. (2001). Happily never after: Young women's stories of abuse in heterosexual love relationships. *Feminism & Psychology*, 11, 305-321.
- Jones, L. (2005). Childcare in poor urban settlements in Swaziland in an era of HIV/AIDS. *African Journal of AIDS Research*, 161-171.
- Kain, P. (1993). Marx, housework and alienation. *Hypatia*, 8, 121-144.
- Kalichman, S.C. & Simbayi, L.C. (2004). Traditional beliefs about the cause of AIDS and AIDS-related stigma in South Africa. *AIDS Care*, 16, 572-581.
- Kelly, K. & Mzizi, T. (2005). The implications of ART for local AIDS care and support programs. *AIDS Bulletin*, 14, 1-8.
- Kestler, H.W., Medley, M. & Horn, T. (2001). HIV, description of. In R.A. Smith (Ed.), *Encyclopedia of AIDS: A social, political, culture, and scientific record of the HIV epidemic* (pp. 327-329). New York: Penguin Books.
- Kim, J.C., (2002). *Rape and HIV post-exposure prophylaxis (PEP)*. Paper presented to the South African Gender-Based Violence and Health Conference, April 17-19.
- Kimberly, J.A., Serovich, J.M. & Greene, K. (1995). Disclosure of HIV positive status: Five women's stories. *Family Relations*, 44, 316-322.
- Kirk, G & Okazawa-Rey, M. (2004). *Women's lives: Multicultural perspectives*. New York: McGraw Hill.
- Kistner, U. (2003). *Gender Based Violence and HIV in South Africa: A Literature Review*. South Africa. Centre for AIDS Development and Research and Evaluation (CADRE)/Department of Health.
- Klitzman, R.L., Kirshenbaum, S.B., Dodge, B., Remien, R.H., Ehrhardt, A.A., Johnson, M.O., Kittel, L.E., Daya, S., Morkin, S.F., Kelly, J., Lightfoot, M., Rotheram-Borus, M.J. &

- The NIMH Healthy Living Trial Group (2004). Intricacies and inter-relationships between HIV disclosure and HAART: a qualitative study. *AIDS Care*, 16, 628-640.
- Kurz, D. (2001). Violence against women by intimate partners. In D. Vannoy (Ed.), *Gender Mosaics* (pp.205-215). Los Angeles, CA: Roxbury Publishing Company.
- Lees, J. (2006, October). *Re-thinking AIDS: Reflections from two decades of work with the pandemic*. Paper presented at University of Cape Town Social Anthropology and University of the Western Cape Sociology and Anthropology Departments Seminar, Cape Town, South Africa.
- Lekas, H.M., Siegel, K., Schrimshaw, E.W. (2006). Continuities and discontinuities in the experiences of felt and enacted stigma among women with HIV/AIDS. *Qualitative Health Research*, 16, 1165-1190.
- Lewis, S. (2006, August). *Remarks by Steven Lewis, UN special envoy for HIV/AIDS in Africa to the closing session of the XVI International AIDS Conference, Toronto*. Message posted to University of the Western Cape list serve, archived at www.allafrica.com
- Lewontin, R., Rose, S., & Kamin, L. (1984). *Not in our genes: Ideology and human nature*. New York: Pantheon.
- Li, L., Wu, S., Wu, Z., Sun, S., Cui, H., Jia, M. (2006). Understanding family support for people living with HIV/AIDS in Yunnan, China. *AIDS & Behavior*, 10, 509-517.
- Lorber, J. & Moore, L.J. (2002). *Gender and the social construction of illness*. New York: Alta Mira Press.
- Mantell, J.E., Dworkin, S.L., Exner, T.M., Hoffman, S., Smith, J.A. & Susser, I. (2006). The promises and limitations of female-initiated methods of HIV/STI protection. *Social Science & Medicine*, 63, 1998-2009.
- Marshall, C. & Rossman, G. (2006). *Designing qualitative research*. Thousand Oaks, CA: Sage.
- Mies, M. (1983). Toward a methodology for feminist research. In G. Bowles & R. Klein (Eds.), *Theories of women's studies* (pp. 117-139). London: Routledge and Kegan Paul.
- Miles, M.B. & Huberman, A.M.. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). Thousand Oaks, CA: Sage.
- Mill, J.E., Anarfi, J.K. (2002). HIV risk environment for Ghanaian women: Challenges to prevention. *Social Science & Medicine*, 54, 325-337.
- Mushunje, M.T. (2006). Challenges and opportunities for promoting the girl child's rights in the face of HIV/AIDS. *Gender and Development*, 14, 115-125.

- Naples, N.A. (2003). *Feminist and method: Ethnography, discourse analysis, and activist research*. New York: Routledge.
- National Woman Abuse Action Project. (1991). *Understanding domestic violence*. Washington DC: National Woman Abuse Action Project.
- Novello, A.C. (1992). *Surgeon General's address to an American Medical Association press conference on violence*: New York.
- Nyblade, L.C. (2006). Measuring HIV stigma: Existing knowledge and gaps. *Psychology, Health & Medicine*, 11, 335-345.
- Nyamukapa, C., Foster, G. & Gregson, S. (2003). Orphans' household circumstances and access to education in a maturing epidemic in eastern Zimbabwe. *Journal of Social Development in Africa*, 18, 7-32.
- Oinas, E. & Jungar, K. (2005, January). *No passive victims! Agents! The concept of victimhood in contemporary feminist debates, particularly in feminist HIV research*. Symposium conducted at the Writing African Women—Poetics and Politics of African Gender Research conference at the University of the Western Cape, Cape Town, South Africa.
- Oxfam International (2007, February). *Oxfam calls for G7 to deliver for Africa*. Retrieved August 21, 2007 from http://www.oxfam.org/en/news/2007/pr070208_g7.
- Oxfam International (2007, August). *Oxfam targeted with email campaign as Novartis' legal action against India approaches climax*. Retrieved August 21, from http://www.oxfam.org/en/news/2007/pr070215_novartis.
- Parker, I. (2004). Discourse analysis. In U. Flick, E.v. Kardorff & I. Steinke (Eds.), *A companion to qualitative research* (pp. 308-312). London: Sage.
- Persson, A. (2005). Facing HIV: Body shape change and the (in)visibility of illness. *Medical Anthropology*, 24, 237-264.
- Petros, G., Airhihenbuwa, C.O., Simbayi, L., Ramlagan, S. & Brown, B. (2006). HIV/AIDS and 'othering' in South Africa: The blame goes on. *Culture, Health & Sexuality*, 8, 67-77.
- Piot, P. (2001). A gendered epidemic: Women and the risks and burdens of HIV. *Journal of American Medical Women's Association*, 56, 609-611.
- Pound, P., Britten, N., Morgan, M., Yardley, L., Pope, C, Daker-White, G. & Campbell, R. (2005). Resisting medicine: A synthesis of qualitative studies of medicine taking. *Social Science & Medicine*, 62, 133-155.
- Provincial Administration Western Cape. (2004). *Antiretroviral Treatment Protocol*. Retrieved March, 1, 2007, from <http://web.uct.ac.za/depts/epi/artrollout>

- Raj, A., Silverman, J.G. & Amaro, H. (2004). Abused women report greater male partner risk and gender-based risk for HIV: findings from a community-based study with Hispanic women. *AIDS Care*, 16, 519-530.
- Ratele, K. & Shefer, T. (2002). Stigma in the social construction of sexually transmitted diseases. In D. Hook & G. Eagle (Eds.), *Psychopathology and Social Prejudice* (pp.185-206). Cape Town: University of Cape Town Press.
- Reddy, S. (2005). "It's not as easy as ABC": Dynamics of intergenerational power and resistance within the context of HIV. *Perspectives in Education*, 23, 11-19.
- Reid, C. & Tom, A. (2006). Poor Women's discourses of legitimacy, poverty and health. *Gender & Society*, 20, 402-421.
- Reinharz, S. (1992). *Feminist methods in social research*. New York: Oxford University Press.
- Reischer, E. & Koo, K.S. (2004). The body beautiful: Symbolism and agency in the social world. *Annual Review of Anthropology*, 33, 297-317.
- Reynolds, N.R., Neidig, J.L., Wu, A.W., Gifford, A.L. & Holmes, W.C. (2006). Balancing disfigurement and disease progression: Patient perceptions of HIV body fat distribution. *AIDS Care*, 18, 663-673.
- Rodin, J. (1993). Culture and psychosocial determinants of weight concerns. *Annals of Internal Medicine*, 119, 643-645.
- Root Aulette, J.L. (2007) *Changing American Families* (2nd edition). New York: Allyn and Bacon.
- Rothenberg, K.R. (1995). Domestic violence and partner notification: Implications for treatment and counseling of women with HIV. *Journal of the American Medical Women Association*, 50, 87-93.
- Salo, E. (2005). Negotiating gender and personhood in the New South Africa: Adolescent women and gangsters in Manenberg Township on the Cape Flats. In S. Robins (Ed.), *Limits to Liberation* (pp. 173-189). London: James Currey.
- Scanlon, J. (1993). Challenging the imbalances of power in feminist oral history: Developing a take-and-give methodology. *Women's Studies International Forum*, 16, 649-645.
- Schwarzer, R., Dunkel-Schetter, C. & Kemeny, M. (1994). The multidimensional nature of received social support in gay men at risk of HIV infection and AIDS. *American Journal of Community Psychology*, 22, 319-339.

- Scrimshaw, E.W. & Siegel, K. (2002). HIV-infected mothers' to their uninfected children: Rates, reasons, and reactions. *Journal of Social & Personal Relationships*, 19, 19-43.
- Siedel, G. (1993). The competing discourses of HIV/AIDS in sub-Saharan Africa: Discourses of rights and empowerment vs. discourses of control and exclusion. *Social Science & Medicine*, 36, 175-194.
- Seidel, G. & Ntuli, N. (1996). HIV, confidentiality, gender, and support in rural South Africa. *The Lancet*, 347, 469.
- Servellen, G.V. & Lombardi, E. (2005). Supportive relationships and medication adherence in HIV-infected low-income Latinos. *Western Journal of Nursing Research*, 27, 1023-1029.
- Sessions, K.B. (2001). United States—The south. In R.A. Smith (Ed.), *Encyclopedia of AIDS: A social, political, culture, and scientific record of the HIV epidemic* (pp. 703-709). New York: Penguin Books.
- Sharma, A., Howard, A.A., Klein, R.S., Schoenbaum, E.E., Buono, D. & Webber, M.P. (2007). Body image in older men with or at-risk for HIV infection. *AIDS Care*, 19, 235-241.
- Shisana, O. & Simbayi L. (2002). *Nelson Mandela/HSRC Study of HIV/AIDS: South African National HIV Prevalence, Behavioral Risks and Mass Media, Household Survey 2002*. Human Sciences Research Council. Retrieved on March 3, 2007, from <http://196.4.93.10/compress/e-library/HIV%20AIDS%20Report%20Executive%20Summary%20for%20web.pdf>
- Smitt, J., Middelkoop, K., Myer, L., Seedat, S., Wood, R., Stein, D.J. & Bekker, L.G. (2006). Sexual risk factors associated with volunteering for HIV vaccine research in South Africa. *AIDS Care*, 18, 569-573.
- Sobo, E.J. (1994). The sweetness of fat: Health, procreation, and sociability in rural Jamaica. In N. Sault (Ed.), *Many mirrors: Body image and social relations* (pp. 132-152). New Brunswick: Rutgers University Press.
- Squire, C. (2007). *HIV in South Africa: Talking about the big thing*. United Kingdom: Routledge.
- Statistics South Africa. (2005). *Mortality and causes of death in South Africa, 2005: Findings from death notification*. Retrieved on July 5, 2007 from <http://www.statssa.gov.za/publications/P03093/P030932005.pdf>.
- Strebel, A. (1995). Whose epidemic is it? Reviewing the literature on women and AIDS. *South African Journal of Psychology*, 25, 12-20.

- Swart, L. & Kagee, A. (2006). Community participation in AIDS vaccine trials: Empowerment or science. *Social Science and Medicine*, 63, 1143-1146.
- Temmerman, M. (1995). The right not to know HIV test results. *The Lancet*, 345, 969-970.
- Terre Blanche, M. & Durrheim, K. (1999). *Research in practice: Applied methods for the social sciences*. Cape Town: University of Cape Town Press.
- Theorell T., Blomkvist, V., Jonsson, H., Schulman, S., Berntorp, E. & Stigendal, L. (1995) Social support and the development of immune function in human immuno virus infection. *Psychosomatic Medicine*, 57, 32-36.
- Tiessen, R. (2005). Mainstreaming gender in HIV/AIDS programs: Ongoing challenges and new opportunities in Malawi. *Journal of International Women's Studies*, 7, 8-25.
- Tostes, M.A., Chalub, M. & Botega, N.J. (2004). The quality of life of HIV-infected women is associated with psychiatric morbidity. *AIDS Care*, 16, 177-187.
- Treatment Action Campaign (2007, April). *APL submissions to human rights commission enquiry into access to health care services*. Retrieved on August 21, 2007 from <http://tac.org.za/documents/ALPsubmissionSAHRChearingsonhealth170407.pdf>
- True, J. (2003). Mainstreaming gender in global public policy. *International Feminist Journal of Politics*, 5, 368-396.
- UNAIDS (2000). *Report on the global HIV/AIDS epidemic*. Geneva.
- UNAIDS (2005). *2005 Report on the global AIDS epidemic*. Geneva.
- UNAIDS, UNICEF & USAID (2004). Children on the brink 2004. *A joint report of new orphan estimates and a framework for action*. Geneva.
- Urdang, S. (2006). The care economy: Gender and the silent AIDS crisis in southern Africa. *Journal of Southern African Studies*, 32, 166-177.
- Van der Straten, A., King, R., Grinstead, O., Serufilira, A., Allen, S. (1995). Couple communication, sexual coercion and HIV risk reduction in Kigali, Rwanda. *AIDS*, 9, 935-944.
- Visser, M.J., Makin, J.D. & Lehobye, K. (2006). Stigmatising attitudes of the community towards people living with HIV. *Journal of Community & Applied Social Psychology*, 16, 42-58.
- Weston, K. (1991). *Families we Choose*. New York: Columbia University Press.
- Weiten, W. (2001). *Psychology Themes & Variations* (5th ed.). United States: Wadsworth.

- Whittaker, A.M. (1992). Living with HIV: Resistance by positive people. *Medical Anthropology Quarterly*, 6, 385-390.
- Wilson, D., Naidoo, S., Bekker, L.G., Cotton, M. & Maartens, G. (2004). *Oxford handbook of HIV medicine*. Cape Town: Oxford University Press Southern Africa.
- Winant, H. (1994). *Racial Conditions*. Minneapolis: University of Minnesota Press.
- Wiss, R. (1994). Lipreading: Remembering Saartjie Baartman. *The Australian Journal of Anthropology*, 5, 11-40.
- Wodak, W. & Meyer, M. (2001). *Methods of Critical Discourse Analysis*. London: Sage Publications.
- Wolf, D.L., ed. (1996). *Feminist dilemmas in field work*. Boulder, Colorado: Westview.
- Wood, S.A., Tobias, C. & McCree, J. (2004). Medication adherence for HIV positive women caring for children: In their own words. *AIDS Care*, 16, 909-913.
- Zezeza, P.T. (2002, July). *Rethinking Africa's gender and globalisation dynamics*. Paper presented at the Women's Worlds Congress, the 8th International Interdisciplinary Congress on Women, Makerere University, Kampala, Uganda.

APPENDIX A

Interview Schedule

Background Info.

When did you find out you were living with HIV?

When did you get involved in the support group?

Why did you decide to participate?

What are some of the benefits of participating?

Have you begun taking ARVs?

What changes would you make to the programme?

Stigma

Broad Question:

Tell me about how the first time you told someone about your status.

Follow-Up Questions:

Who did you disclose your status to since you entered the program?

How did you go about telling the people closest to you about your positive test?

How did these people react to what you told them?

What kind of counseling did you receive before doing this?

Do the people in your community know your status?

Tell me about any forms of stigma that you have faced?

Do you think you will face stigma in the future because of your HIV status?

How do people react to you when they find out you are in the ARV programme?

Do you discuss stigmatisation with counselors at the clinic or in this support group?

How have the counselors at this facility helped you to deal with stigmatisation?

Emotional affects on physical well- being

Broad Question: Tell me about how your everyday life has changed since your diagnosis.

Follow-Up Questions:

What has been the most difficult part of life regarding HIV?

What do you worry about the most since your diagnosis?

What kind of anxiety or worries have you had since joining the support group/ARV programme?

Who has helped you with any of these problems?

Which of these issues have you discussed with facilitators of the support group or the staff at the ARV clinic?

Has the programme given you some tools for dealing with anxiety?

How does stress interfere with your ability to take care of your health?

Violence

Broad Question: Tell me about the women you know who have been in abusive relationships.

Follow-Up Questions:

Do you know any women who became infected with HIV when they were in an abusive relationship with a man?

How did they find help?

How could the support group of clinics help them more?

Have you ever been in an abusive relationship?

Who helped you? How did you help yourself?

When you learned of your HIV positive diagnosis, what did you speak about with the counselors?

Were any abuse issues mentioned?

What issues related to HIV or your treatment plan that are upsetting to you that you have not been able to discuss or that have not been addressed by the clinics or support groups?

Do you feel that your voice is heard when you have questions or concerns regarding your medical treatment?

APPENDIX B

Informed Consent Form

Researcher Info.

My name is Anna Aulette-Root and I am conducting research on women's opinions on the psychological support and care they have received concerning becoming infected with HIV/AIDS and living with the virus. I am doing this research as a Masters Thesis in the Department of Psychology at the University of Cape Town. I hope that this research will help to provide more comprehensive care for women in enrolled in ART programmes in the Western Cape. Dr. Floretta Boonzaier is supervising this research and can be contacted at the UCT Department of Psychology in the Graduate School of Humanities Bldg.:

Dr. Floretta Boonzaier: 650-3429, floretta@humanities.uct.ac.za

Anna Aulette-Root: 072-989-6717, aaulette@gmail.com

Data Collection

All interviews will be tape recorded and later transcribed. The information that I collect from your interview will be analysed and possibly directly quoted in the final research paper that I submit as my thesis. Once I have transcribed the tapes, I will destroy them for your confidentiality. You can also request that I destroy the transcripts at a later date if you choose. If you choose to participate in an interview, I will not reveal your name in the research paper or to anyone at any time. The only identifying factor that I will mention in the paper is that all of the individuals I interview are in ART treatment programmes in the Western Cape.

I,.....agree to participate and have not been pressured into an interview with Anna Aulette-Root and I understand that:

- I can end the interview at any time with no penalty or consequences.
- Everything that I say during the interview will remain confidential.
- At no time will my name or any other identifying factors (with the exception of the fact that I am in an ART programme in the Western Cape) be revealed to anyone.
- Tapes of my interview will be destroyed after they are transcribed.
- The information and possibly quotes from my interview will be included in a research paper written by the interviewer and submitted to the professor mentioned above.
- I can request a copy of the final research paper at a later date if I choose.
- My participation in this interview is completely voluntary.

Participant Signature.....Date...../2006

Researcher Signature.....Date...../2006

University of Cape Town