

An Exploration of the Stigma Experienced by Women who are living with HIV/AIDS

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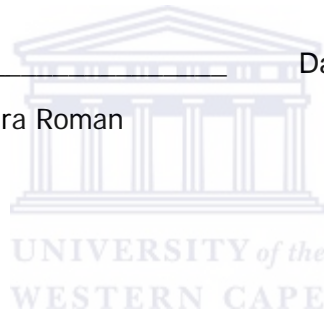
2006

DECLARATION

I hereby declare that this thesis titled "**A case study of the Stigma experienced by Women who are living with HIV/AIDS in Guguletu and Mitchells Plain**" is my own work and that I have not submitted it, or part of it, for any degree or examination at any other university. All sources and significant contribution that I have quoted have been indicated and acknowledged by means of references.

Signature: _____ Date: _____

Gail Sandra Roman



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KEY WORDS

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HIV/AIDS

Guguletu

Mitchells Plain

Discrimination

Poverty

Disclosure

Gender

Community

Relationships



ABSTRACT

The effects of the spread of HIV/AIDS place a great burden on women and children, who will probably suffer most in terms of social and economic deprivation. Since HIV/AIDS is linked to social taboos such as sexuality, drug use and death, there are enormous levels of ignorance, denial, fear and intolerance in most communities. These prejudices lead to the stigmatisation and discrimination of people who are living with HIV/AIDS. Moreover the illness, as it is sexually transmitted, has been conflated with sexual excess, lack of morals, and those already stigmatised such as sex workers with associated discourses of blame, shame and guilt. Generally, responses to HIV and those living with HIV have served to reflect, legitimise and reproduce broader social inequalities on the basis of sexual orientation, gender, race and class. Stigma is the reason why many people who are living with HIV/AIDS, choose not to disclose their status and seek apposite assistance. The purpose of this study was to explore the stigma experienced by a group of women who are living with HIV/AIDS and to develop a deeper understanding of whether these experiences are complicated by social responses. This study presents a focus on how negative responses have impacted on these women.

The study employs feminist qualitative research methods. The data was collected through six focus group discussions, which were held with a total

number of 36 women who are living in Guguletu and Mitchells Plain, two suburbs in Cape Town. One of these suburbs is historically African and one historically Coloured and both are still predominantly low-income, disadvantaged areas. Qualitative thematic analysis was used to analyse and interpret the data. All standard social science ethical procedures were followed in dealing with participants.

The findings are presented within a number of broad thematic areas, including: women's experiences of living with HIV/AIDS; stigma and gendered stigma impacting on women; and experiences of living with HIV and coping with responses from the community, including health care workers, the family and community and support structures. The research findings are discussed within a greater theoretical body of knowledge and considered in the light of contexts, which are considered influential in impacting the experiences of stigma. The findings reveal that women who are living with HIV experience widespread stigmatisation. Although stigmatising attitudes are not always expressed in words, they are nevertheless obvious to those who are living with HIV. The participants of this study reflected that they are treated differently; are frequently avoided; and spoken about in their absence. Even in the health sector, the very place that one would expect to find expertise, confidentiality and to be met without prejudice, there are reports of HIV positive patients experiencing some form of victimisation. This study reveals the thoughts and experiences of a group of women living with HIV/AIDS, and includes both

their negative experiences and aspects of their lives that have facilitated more positive experiences such as support groups. In response to the need to reflect upon related stigma, the findings have implications for effective intervention to care for and assist women who are living with HIV/AIDS.

Those who own information, knowledge, financial means and the political will to make a difference can only solve the problem if there is a global will to do so. Global initiatives matched with grassroots initiatives where local people are part of the solution, will lessen the impact of living with the disease. What emerges from this study is the fact that the role of men needs to be addressed. Given the powerful role of men in society, HIV/AIDS interventions and strategies targeting men will have a substantial impact on reducing the vulnerability of women to HIV.

This study forms part of a broader research project into stigma and HIV/AIDS conducted by PennState University, Human Science Research Council and University of the Western Cape.

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CHAPTER 1

INTRODUCTION

'South Africa is the latest country in the ranks of those seeking to break through the shroud of stigma and shine a light on the human disaster of AIDS'

UNAIDS/AIDS Epidemic Update, December 1998

1.1. Introduction

More than 15 years ago Human Immunodeficiency Virus (HIV) was linked to and identified as causing AIDS (Piot & Seck, 2001) and the last few years have seen a major increase in the scope and scale of the national, regional and international response to HIV/AIDS (UNAIDS/WHO, 2004). There is a growing recognition that globally a major catastrophe is upon us. HIV/AIDS has exposed the many global and national inequalities and unjust systems that we have come to accept as normal (Nouwen, 1992). Global estimates of the HIV/AIDS pandemic have revealed that more than 60 million people worldwide have lived with HIV/AIDS and 20 million have died of the disease (UNAIDS, 2003). The latest global AIDS and HIV statistics published by UNAIDS in December 2005 reported a total of 40.3 million people living with HIV in 2005, of which 17.5 million are women (UNAIDS, 2005). These statistics are devastating, not only for families and communities but also for the broader society and economy.

Grundlingh (2001) argues that at first in South Africa, as in the international context HIV/AIDS was viewed as a homosexual disease, a disease of drug users, and later a disease of the Black and poor communities. The history of HIV/AIDS in South Africa is therefore rooted in a framework couched in a discourse of deviancy and it has always been evident that HIV/AIDS exposed and intensified social prejudices, stereotypes and economic inequalities, discriminatory practices and political injustices both nationally and internationally (Seidel, 1998; Grundlingh, 2001).

The AIDS pandemic in South Africa is not only a major public health crisis but also a threat to economic development and social solidarity. South Africa, which is home to more HIV-positive people than any other country in the world, is a particularly interesting case in point. According to Nattrass (2004) more than one in five adult South Africans is HIV-positive and AIDS deaths are expected to rise sharply until 2010. Over a million children could be orphaned by 2015 as a result. HIV/AIDS has been described as a medical and a social disease (Simbayi, 2002). The scourge of HIV/AIDS has affected all aspects of South African society (Kauffman & Lindauer, 2004). It has been asserted that the prevalence and spread of the epidemic is largely determined by many powerful social, political, structural as well as economic factors (Shisana, Rehle, et al., 2005).

Various authors in the South African National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey (2005) cited that Sub-Saharan Africa is severely impacted by the HIV/AIDS pandemic. Recent estimates suggest that of

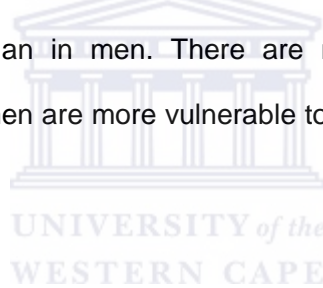
all people living with HIV in the world, six out of every ten men, five out of every ten women, and nine out of every ten children live in sub-Saharan Africa. These figures provide sufficient evidence to make HIV/AIDS both a sub-Saharan and South African priority (Shisana, Rehle, et al., 2005).

It was reported that Sub-Saharan Africa has just over 10% of the world's population, but is home to more than 60% of all people living with HIV 28.8 million. In 2005, an estimated 3.2 million people in the region became newly infected, while 2.4 million adults and children died of AIDS. Among young people aged 15-24 years, an estimated 4.6% (4.2 – 5.5%) of women and 1.7% (1.3-2.2%) of men were living with HIV in 2005 (UNAIDS 2006). A reputable South African weekly newspaper quotes in their HIV/AIDS barometer, an estimated 1 808 148 AIDS-related deaths in South Africa as at 7 June 2006 (Mail & Guardian, 9-15 June 2006). Based on the results of many surveys, including the household and antenatal studies, UNAIDS/WHO (2005) made their own estimate of 18.8% prevalence in those aged 15-49 years old, at the end of 2005. Their high and low estimates are 16.8% and 20.7% respectively. According to their own estimate of total population size, approximately 5.5 million South Africans were living with HIV at the end of 2005 (UNAIDS/WHO, 2006).

An article in the Cape Argus, October 19, 2005 revealed that the Western Cape continues to face a serious HIV threat, and the national statistics reveal cases have almost doubled since 2001. Most shocking, perhaps, was the fact that nearly 40% of women aged 25 and 29 who presented themselves to ante-natal

clinics in October last year, are HIV positive. The figures for women in their early 20s and early 30s show a slightly lower 30% prevalence rate, but that still accounts for nearly one in every three pregnant women. Extrapolating the results to the general population, the researchers said they estimated that 3.3 million women and 2.8 million men, as well as more than 100 000 children were living with HIV (Cape Argus, 2005).

According to a report by the National Centre for HIV, STD and TB Prevention (2003), HIV infection and AIDS were diagnosed for relatively few women in the early days of the epidemic. Today, according to the report, the HIV/AIDS epidemic represents a growing and persistent health threat to women, especially young women and women of colour. In Africa, HIV infection has been spreading more rapidly in women than in men. There are many socio-economic and biological reasons why women are more vulnerable to the HI virus. (S.A. Dept. of Health Study, 2004).



The burden of HIV/AIDS has clearly not fallen evenly. The disease has hit the poor and marginalized hardest (Walker & Gilbert, 2002). More specifically, the United Nations AIDS Epidemic Update of December 2003 exposed that of the millions living with HIV/AIDS in South Africa, African women bear the brunt of the illness (UNAIDS, 2003).

South African society remains extremely patriarchal and gender-based social norms define acceptable behaviour, relationship characteristics and role

responsibilities. Local research has demonstrated how these social norms translate into gender power imbalance. This imbalance increases the vulnerability of women to HIV infection (Vetten & Bhana, 2001; Jewkes, Levin, Loveday & Kekana, 2003; Walker & Gilbert, 2002b; Strebel, 1993). Women experience lack of power and control over general decision-making in homes and in communities. Additionally women have little or no control over their lives sexually, facilitating increased risk for contracting HIV (Macphail & Campbell, 2001). In South Africa, great social inequalities and societal imbalances exist. These determine that women are the most susceptible to infection (Walker & Gilbert, 2002b).

Women and girls are therefore increasingly at risk of becoming HIV positive due to biological vulnerabilities as well as unequal gender relations and other factors (De Bruyn, 1992). Gender-related issues, which are known to increase the risks of HIV infection among females in South Africa as they do internationally include the low social status of women and economic dependence on men (Grieser et al., 2001; Matchaba, 2000; Mitton, 2000). These factors affect women's capacity to determine their sexual lives (Meyer-Weitz et al., 1998; Strebel, 1995; UNAIDS/WHO, 1993), with sexual decision-making being constrained by coercion and violence (HIV InSite, 2001; UNAIDS/WHO, 2000).

1.2. Statement of the Problem

Stigmatisation, 'othering' and blaming often mark the HIV/AIDS discourses in Africa as they do internationally (Grinstead, Gregorich, Choi & Coates, 2001;

Haram, 2001; Leclerc-Madlala, 2001; Morron, Costello & Boland, 2001; Rabinowitz & Canale, 2004; Withell, 2000). Heath & Rodway (1999:45) defines the disease as a 'mark of shame or discredit' and it is stigma that places HIV/AIDS apart from other chronic or terminal diseases. It is often associated with unacceptable lifestyles and activities such as prostitution, indiscriminate sex with multiple partners, and 'loose' morals (Heath & Rodway, 1999:45). Researchers have concluded that the disclosure of an HIV-diagnosis raises crucial issues regarding stigma, discrimination, diminution in self-esteem and various conflicts and experiences of loss arising at different stages of the disease (Dean, 1995; Leask, Elford, Bor, Miller & Johnson, 1997; Macks, 1987; McGinn, 1996; Schurink, 1990; Sewpaul & Mahlalela, 1998; Zlotnik, 1987).

It has been argued that people and especially women, who live with HIV/AIDS, are exposed to stigma and discrimination at community and family level (Achmat 2001; Johnston 2001; Qwana et al., 2001; UNAIDS/WHO 2000) as well as by health personnel (Fransman et al., 2000). Women contracting HIV experience marginalisation as they become the recipients of rejection, stigmatisation, and isolation and are ostracised as a result of the social unacceptability of HIV (Orr & Patient, 2004).

For these reasons this study is an attempt to deepen understandings of the lived experiences of stigma for South African women living with HIV/AIDS. This study aims to contribute to research which has focussed on the understanding of the impact that stigma has on women and how to best challenge it, bringing about an

increased sensitivity to stigma and to facilitate more positive experiences of living with HIV/AIDS.

1.3. Outline of Thesis

The **introductory chapter** presents the context and rationale for the present study providing a broad understanding of HIV and its prevalence in South Africa and contextualising the focus on women living with HIV/AIDS and stigmatisation.

Chapter 2 provides a conceptual framework from which this research has been launched, critically examining the wider debates that relate to the topic researched. In this chapter an understanding and definitions of stigma are presented, literature on women's experiences of living with HIV/AIDS are outlined, and the experiences of stigma faced by them are examined.

Chapter 3 provides an overview of how the study was conducted presenting the methodology of choice which is defended. Procedures for data collection, data analysis, ethical issues, demographics and a discussion on self-reflexivity are presented.

Chapter 4 presents the research findings and analysis of the study encapsulated in themes emerging from the data and including illustrative quotes from participants. An illustration of the world of the participant, which focuses on the lived experiences of stigma and which is constituted by their interpersonal relationships, is provided.

Chapter 5 concludes the study and presents recommendations that emerge for future research and interventions. Comment is made regarding the limitations of the study and a final summary of the study is presented.



CHAPTER 2

CONCEPTUAL FRAMEWORK AND LITERATURE REVIEW

It is widely recognised that women are more vulnerable to HIV/AIDS (Vetten & Bhana, 2001; DFID, 1998; Outwater, 1996; Strebel, 1993; de Bruyn et al., 1998). Women's vulnerability is mainly entrenched in their 'social, sexual and economic' position (de Bruyn et al., 1998:10). Moreover, it appears that they are also subject to more intense victimisation and stigmatisation in their experiences of living with HIV/AIDS. This chapter provides an understanding of the social, economic, sexual and biological vulnerabilities of women living with HIV/AIDS. Furthermore, the literature in this chapter demonstrates and explores the stigmatisation processes and the impact of these on women who are living with HIV/AIDS.

2.1. Women are more susceptible to HIV/AIDS

What is clear from various research studies and as outlined in the introductory chapter is that there is a severe epidemic of HIV/AIDS in South Africa. This epidemic affects all parts of the population, though, according to Walker & Gilbert (2002b), women are the most susceptible to infection and most disadvantaged with respect to the care of those living with HIV. Even though this study's focus is on the experiences of stigma of women living with HIV/AIDS, it is important to contextualise the study in a broader understanding of women's vulnerability to infection.

Women's vulnerability to HIV/AIDS stems from a range of social, economic, biological, cultural and legal factors (Buzy et al., 1996; de Bruyn et al., 1998; Take Control, 2001b; Long & Ankrah, 1996; Outwater, 1996).

The odds against women and girls remain great in Africa. African women still live largely in a world where they have to prove their worth by being married, having children and caring for their families (Esu-Williams, 2000). Therein lies their vulnerability to HIV/AIDS (Urdang, 2001). Esu-Williams (2000) posits that African women need to be liberated from the mentality with which they are conditioned to grow up, in particular the notion that their lives are less of a priority than those of the male partners. Within social and cultural contexts, women affected by HIV/AIDS are often faced with no means to confront the denial of their basic rights, including the right to property, to their children and to produce the means to their own livelihood (Esu-Williams, 2000).

In Africa and South Africa, HIV/AIDS is overwhelmingly distributed by heterosexual transmission. Women and children are the most vulnerable targets of HIV/AIDS (Urdang, 2001). Women and girls are increasingly at risk of becoming HIV positive due to biological vulnerabilities as well as unequal gender relations and other factors (De Bruyn, 1992; UNAIDS, 2003). Young African women are considered 'most susceptible to infection, have the highest rate of infection, get the most inadequate and inferior access to treatment, take the most responsibility for caring for the sick and dying, and have the shortest survival rates' (Walker & Gilbert, 2002:75).

There is a growing global understanding that HIV/AIDS is less about infection and more about social, economic and cultural factors (Urdang, 2001). Women have been passive in sexual relationships, with little participation in decision-making or suggestions relating to their role in sexual activity. However, such traditionalist views on sexuality and gender hold little currency in the modern world, especially when sexual activity can lead to HIV infection and disastrous consequences for a woman and her children (Rhodes & Cusick, 2000). Henderson (1996) argues that enlightenment and liberation is essential for women, who can play a vital role in persuading their partners to employ safer sexual practises aimed at reducing infection risk.

In an attempt to categorise women's vulnerability to HIV/AIDS (Tallis, 1998:93) describes their societal vulnerability. The author alludes to the larger framework in which women operate on a day-to-day basis including 'gender relations, attitudes towards sexuality, the political situation, culture, tradition, religious beliefs and poverty' which all contribute to women's heightened vulnerability to HIV/AIDS (Tallis, 1998:93).

2.1.1. The Biological Context

Biology makes women anatomically and physiologically more vulnerable to contract HIV/AIDS than men. The risk of becoming infected with HIV during unprotected sex is two to four times greater for a woman than for a man (Women's International News Network, 2002; Gennrich, 2004). Male to female transmission is more likely because during vaginal intercourse a woman has a

larger surface area of her genital tract exposed to her partner's sexual secretions than does a man. HIV concentration is generally higher in male semen than in a woman's sexual secretions (Women's International Network News, 2002). The vagina and cervix of young women are less mature and are less resistant to HIV and STI's than adult women, meaning that young women are particularly at risk. Furthermore, changes in the reproductive tract during puberty make the tissue more susceptible to penetration by HIV. Hormonal changes associated with menstrual cycle often are accompanied by a thinning of the mucus plug, the protective sealant covering the cervix. Such thinning can allow HIV to pass more easily. Young women produce only scant vaginal secretions, providing little barrier to HIV transmission (Women's International Network News, 2002).

Women are more likely to bleed or bruise during violent or rough sex, which makes them more likely to become infected not only with HIV but with other sexually transmitted diseases as well. Gupta (2000) asserts that menstruation makes women more vulnerable to contracting HIV. Sexually transmissible infection (STI's) are readily acquired during this time. However, according to Strebel (1995) these remain undetected resulting in inefficient treatment that in turn increases the risk of HIV infection. Accessing services for STI's is perceived as being highly stigmatising. Consequently many women do not seek treatment. In the presence of STI's the risk of contracting HIV is greatly increased (Gupta, 2000).

2.1.2. HIV/AIDS, Gender and Poverty

Notwithstanding biological vulnerability, central to women's vulnerability to infection are economic factors. Inter Press Service (2000) asserts that although the conjunction of HIV with poverty has contributed to stigmatising and 'othering' processes, there is no doubt that poverty intersects with gender to create a particular vulnerability for women. In South Africa, there is some correlation between extreme poverty and high HIV prevalence, although the virus is prevalent across all sectors of society (Inter Press Service, 2000).

Many women live under conditions of immense poverty and have very limited choices when it comes to negotiating sexual relationships with men about when and how sexual intercourse takes place (Lesetedi, 1999; Meyer-Weitz et al., 1998; Strebel, 1995; Gupta, 2000). Major problems arise when male partners either have sex with sex workers or engage in multiple relationships. Their female partners or spouses cannot insist on them using condoms when they have sexual intercourse due to fear of losing their main source of livelihood. Faced with no alternative to earn their livelihood, many women are left unprotected from HIV infection from their promiscuous male partners (Simbayl, 2002).

Women's lack of economic power enables their sexual exploitation through sex working and 'sex for favours' and female sex workers are in a very high-risk group (Strebel, 1995). Women who desperately need money to care for their children, many of them widowed by AIDS, are not in a position to insist that their

customers wear condoms. They are not only at risk of becoming infected with HIV, but if they are already HIV positive, the virus can be transmitted to their partners (Strebel, 1995; Gupta, 2000). Women's economic dependence increases their vulnerability to HIV. The economic vulnerability of women makes it more likely that they will exchange sex for money or favours, less likely that they will succeed in negotiating protection and less likely that they will leave a relationship that they perceive to be risky (Gupta, 2001).

Like so many other infectious diseases, HIV/AIDS is partly a disease of poverty and South Africa's history of inequity and social dislocation has clearly contributed to the severity of the epidemic. HIV/AIDS prevention programmes cannot address these broader complexities directly, but they must take cognisance of this context within which the infection of HIV/AIDS is spread (Harrison, Smit & Myer, 2000).

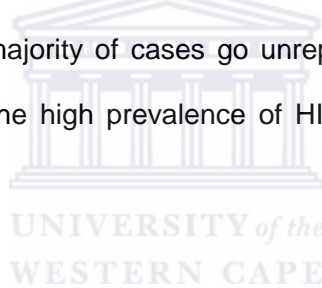
Poverty in developing countries continues to affect more women and children than men. Poverty also increases the vulnerability of these women and children to HIV infection.

2.1.3. HIV/AIDS, Gender and Power

Intersecting with the economic factors is the centrality of gender power inequality and traditional gender roles in women's ability to negotiate safe sex. Cultural and religious beliefs, which perpetuate a gender power imbalance, are those that insist that women should obey their husbands at all costs, and beliefs that men

'naturally' need more than one sexual partner, make it difficult for wives to insist on their husbands' faithfulness or to refuse unsafe sex, even within a marriage relationship (Haddad, 2002; NPPHCN, 1995; Wood & Foster, 1995).

Although HIV prevention campaigns usually encourage people to use condoms and reduce their number of sexual partners, women and girls in South Africa are often unable to negotiate safer sex and are frequently involved with men who have a number of sexual partners. They are also particularly vulnerable to sexual abuse and rape, and are economically and socially subordinate to men. Police reports suggest that in 2004-2005 there were 55,114 cases of rape in South Africa (Crime Information Analysis Centre, Rape in the RSA for the period April to March 2001/2002 to 2004/2005). Although the actual figure is undoubtedly larger than this since the majority of cases go unreported. This major problem plays a significant role in the high prevalence of HIV among women in South Africa.



The double standards highlighted in many South African studies, e.g. (Strebel, 1993; NPPHCN, 1995; Shefer, 1999) further facilitate women's vulnerabilities to STI infections. Many women have STI's as a result of the accepted practise within South Africa. Within some communities South African men have other lovers with whom they have unprotected sexual intercourse (Haour-Knipe & Aggleton, 1998).

Women experience difficulty in saying no to unwanted and unprotected sex. The Joint Monitoring Committee on the Improvement of the Quality of Life and Status of Women (JMCIQLSW) held hearings in October and November 2001 on 'How best can South Africa address the impact of HIV/AIDS on women girls?' The Committee's priority is to monitor how government is addressing the impact of poverty, HIV/AIDS and violence on women. The Committee heard that women who are trying to get men to adhere to the "A,B,C" approach: Abstain, Be faithful, Condomise, face rejection, beating and even death. Women's sexual autonomy is challenged where so many socio-cultural barriers exist (Report of The Joint Monitoring Committee, 2001). Women are ostracised, discriminated against and abused due to unequal power in gender relations (Urdang, 2001).

Gennrich (2004) posits that men's traditional role as the 'provider' and 'protector' of women and children in their society has been eroded by the high unemployment rates and by poverty. Some men turn to violence to prove their dominance over women and children. According to Haddad (2002), South Africa has the highest incidence of rape and other violent crime in the world. Recent estimates are that one woman is raped every 17 seconds. In South Africa and elsewhere in the region, the rape of young girls and babies has been presented in the media as resulting from the apparently widely accepted belief that sex with virgins is a way of curing or protecting against HIV/AIDS (Love Life, 2000; Vetten & Bhana, 2001).

Generally, a strong relationship between HIV infection and gender-based violence and coercive sexual practises has been well established (for example Vetten & Bhana, 2001). There has been a proliferation of research in South Africa on violence against women, and an increasing focus on the intersection between violence, 'normal' heterosexual practices and HIV/AIDS infection (Meursing et al., 1999; Vetten & Bhana, 2001; Take Control, 2001). Sexual violence against women and girls, whether by known or unknown rapists, is ubiquitous. Coercive sexual practises and abuse have been increasingly reported in studies exploring heterosexual negotiations and practises (Burry et al., 1992; Dorn et al., 1994; DFID, 1998; Vetten et al., 2001). The challenges for girls and women for safe sex negotiations in the light of such practices have been widely reported in local literature (Shefer, Strebel & Foster, 2000).

In a PACSA report (2003), a research study with thirty semi-rural women near Pietermaritzburg, 13 of these women (40%) claimed to have been forced into sex by their partner. Of these, 8 (nearly 60%) were not able to use any form of protection against HIV or other sexually transmitted diseases. Women who are in sexually abusive relationships may be less able to negotiate safer sex than others. Although this is a small sample, there are wide ranges of research findings that highlight the key role that coercive sexual practices play in HIV/AIDS. In many societies in the African context, there is a culture of silence that surrounds sex that dictates that 'good' women are expected to be ignorant about sex and passive in sexual interactions (Gupta, 2001). This makes it difficult for women to be informed about risk reduction, or makes it difficult for them to be

proactive in negotiating safer sex and resisting coercive sexual practices. Young girls often endure sexual coercion and abuse (Women's International Network News, 2002). In Kenya, for example, 40% of sexually active female adolescents reported that they had been forced into sex (Gupta, 2001).

The vulnerability of women in the context of gender inequality is a crucial component in slowing down the spread of HIV/AIDS (Women's Health Weekly, 2000). South African studies have found that women are viewed and view themselves as 'sluts' or 'loose' if they are sexually active and take multiple partners, while such behaviour determines manhood for a man (Strebel, 1993; Shefer, 1999). This language also reproduces female sexuality as receptive, categorising women as either pure or impure (Shefer, 2001). According to Shefer (2001:10), 'sexuality gets framed as a male domain, in which men control and set the terms, and to which women must be inducted and guided' (Shefer, 2001:10). This depicts the well-known theme of the male actor and the waiting virgin. Shefer (2001) argues that 'there is a need for the development of discourses which challenge the negative construction of girls'/women's sexuality and sexual desires, and put forward a positive acknowledgement of women as sexual agents' (Shefer 2001:14).

2.2. Stigma & HIV/AIDS

Many researchers have found that the disclosure of an HIV-diagnosis raises crucial issues regarding stigma, discrimination, isolation, alienation, reduction in self-esteem and various conflicts, and losses arising at different stages of the

disease (Dean, 1995; Dicks, 1994; Dukes & Denny, 1995; Ewing, 1994; Jue, 1994; Kelly & Lawrence, 1988; Kiemle, 1994; Leask, Elford, Bor, Miller & Johnson, 1997; Macks, 1987; McGinn, 1996).

Leenerts & Magilvy (2000), and Sowell et al. (1999) assert that experiences of stigmatisation affect health outcomes, including mental health and quality of life.

2.2.1. Defining Stigma

Jones et al. (1994) posit that stigma is a 'mark' that links a person to undesirable characteristics or negative stereotypes. According to Stafford & Scott (1986:80) stigma has been defined as 'a characteristic of persons that is contrary to a norm of a social unit'.

Stigma, defined as a 'construction of deviation from some ideal or expectation' (Alonzo & Reynolds, 1995:304), has been described as marginalizing and excluding individuals from groups because of a specific attribute (Taylor, 2001). Attributes could be physical deformities, blemishes of individual character or framed within racial, religious or national identities (Goffman, 1990).

Even though the words stigma and discrimination are often used interchangeably, their meanings differ. Discrimination focuses on behaviour and practices: the 'unjustifiably different treatment given to different people or groups' (Manser & Thompson, 1999:369). Stigma is defined as a process in which an attribute or quality is utilised to 'significantly discredit' an individual in the eyes of

others. Importantly, stigma is a process. Within a particular culture or setting, certain attributes are seized upon and defined by others as discreditable or unworthy (UNAIDS, 2000).

‘Stigma is an exercise of power over people. It acts to reinforce social norms thereby defining deviance’ (Taylor, 2001:794). Stigma and stigmatisation are most easily understood as social processes, which play a key role in producing and reproducing relations of power and control in social systems. Stigma is therefore linked to social inequality. Stigma operates in relation to already existing differences in societies. By making social inequalities seem reasonable, it creates and reinforces social exclusion (The Policy Project, 2003).

In addition, Gilmore & Somerville (1994) and Alonzo & Reynolds (1995) conceptualise stigma with a focus on social constructions of inequality. They argue that stigma accordingly serves an ‘exercise of power’ to reinforce socially constructed norms for what is acceptable and desirable, by defining what is deviant, and excluding those that are found to be deviant (Gilmore & Somerville, 1994:1342).

Furthermore, the ‘stigmatised’ are defined by Alonzo & Reynolds (1995:304) as: ‘a category of people who are pejoratively regarded by the broader society and who are devalued, shunned or otherwise lessened in their life chances and in access to the humanizing benefit of free and unfettered social intercourse’.

Parker & Aggleton (2003) argue that when definitions of stigma have been offered to HIV/AIDS stigma, they have been relatively limited. The authors further assert that stigma plays a key role in producing and reproducing relations of power and control. It operates to legitimise the devaluation of some groups and the construction of superiority by others. Stigma is linked to the workings of 'social inequality' and a proper understanding of issues of stigmatisation and discrimination, whether in relation to HIV/AIDS or any other issue, requires a broader perception and notion about how some individuals and groups come to be socially excluded, and about the forces that create and reinforce exclusion in different settings (Parker & Aggelton, 2003).

2.2.2. HIV/AIDS related Stigma

The prevalence of misinformation about AIDS and associated stigmatisation in South Africa has not only hampered efforts to increase access to treatment, but has also created a climate of confusion in which prejudice towards people living with HIV thrives.

In South Africa, by 1998, although people from more affluent, largely white society were starting to 'come out' as being HIV positive, stigmatisation of the condition remained still deeply rooted in township areas. In October of that year, the then Deputy President Thabo Mbeki made the Declaration of Partnership against AIDS, in which he called for an end to discrimination against people living with HIV (Declaration of Partnership against AIDS, 1998). However, it was clear that there was a long way to go before this goal could be achieved. Less than

two months later, Gugu Dlamini, an AIDS activist in Durban, was beaten to death by her neighbours after declaring that she was HIV positive on World AIDS Day.

The stigma surrounding HIV/AIDS is such that, in the Western Cape Province, the area in which this study has been conducted, HIV/AIDS is called 'ulwazi' which means 'that thing'. HIV/AIDS is seen, not only as a disease that has no cure, but also as one, which is so stigmatised, that it cannot even be referred to by name (Morgan, 2003).

In the high-density urban areas of Zimbabwe, if one is suspected of being HIV-positive, people use street slang, such as '*Akarohwa nematsotsi*' (describing the infected person as beaten up by thieves). Some of the music on HIV/AIDS exacerbates the stigmatisation of PLWHA, using war language and disaster metaphors (Chisango, 2004).

The stigma attached to HIV because of the association of HIV with immorality, promiscuity, dirtiness and sin (Sontag, 1991) is experienced by those living with HIV/AIDS. As a result of the associated stigma, many people who live with HIV face rejection from the family. Unsatisfactory interpersonal relationships within the family and a lack of support are then experienced.

In 2000, Justice Edwin Cameron of the South African court announced in a speech that he was HIV positive. The public response to this declaration was, largely supportive. However, coming out as HIV positive can in many cases have

a negative effect on employment and housing opportunities, as well as social relationships. A study in 2002 revealed that only one third of respondents who had revealed their HIV positive status were met with a positive response in their communities, while one in ten reported that they had been met with hostility and rejection (Steinberg & Johnson, et al., 2002).

When his son died of AIDS in 2005, Nelson Mandela publicised the cause of his death in an effort to challenge the stigma that surrounds HIV infection, 'let us give publicity to HIV/AIDS and not hide it, because that is the only way to make it appear like a normal illness' (BBC.Co.UK, 2005).

It is argued that following cancer, AIDS has emerged as a disease 'whose charge of stigmatisation, and whose capacity to create spoiled identity, is far greater' (Sontag, 1991:101). A review of studies by Crawford (1996) indicates that a greater degree of stigma is directed towards individuals who are living with HIV/AIDS than towards individuals with comparable diseases.

Hikaum (2004:8) posits that around the world, HIV/AIDS related stigma is expressed through 'social exclusion, personal rejection, direct and indirect discrimination and harassment', and laws that deprive people living with HIV/AIDS of their rights. It is further asserted that this may include denial of personal dignity and services or rights, such as employment, housing, insurance, education, health care and travel. The association of HIV/AIDS with sex, disease, death and behaviours which are considered deviant or taboo, such as extra-

marital sex, homosexuality and drug use are factors which contribute to the stigmatisation of people who are living with HIV/AIDS. Stigma, according to Hikuam (2004:8) is further 'fuelled by the myths and misconceptions around HIV transmission'.

HIV/AIDS-related stigma is a real or perceived negative response to a person or persons by individuals, communities or societies. It is characterised by rejection, denial, and discrediting, underrating or social distance. Stigma with respect to HIV/AIDS is associated with disgrace or shame. Stigma, therefore often leads to discrimination, which in turn, leads to human rights violations for people living with HIV/AIDS and their families (Seale, 2004).

External stigma refers to actual experiences of discrimination. This includes oppression, the exercise of power and control, accusation, blame and exclusion. Internal stigma is the shame associated with HIV/AIDS that is the internalisation of some of the negative constructions and stigmatising processes within social responses to those living with HIV/AIDS. It may facilitate the protection of self from enacted or external stigma and often results in refusal or reluctance to disclose HIV status, or the denial of HIV/AIDS and unwillingness to seek help (UNAIDS, 2000).

2.2.3. Gendered HIV Stigma

As has been shown gender roles around the world categorise women into positions where they lack the power to protect themselves from HIV infection. It

has been widely recognised that gender is not a synonym for sex (Gupta, 2001). It refers to widely shared expectations and norms within a society about appropriate male and female behaviour, characteristics and roles. It is a social and cultural construct that differentiates women from men and defines the ways in which women and men interact with one another. Gender is a culture specific construct (Gupta, 2001). Traditional constructions of gender support the notion that men are seen as being responsible for the productive activities outside the home, while women are expected to be responsible for the reproductive and productive activities inside the home. Women have less access than men, over the control of productive resources such as income, land, finances and education.

It is arguable that women are not only at greater risk of infection, but are also disproportionately affected by HIV and AIDS in South Africa. Walker, Reid & Cornell (2004) argue that in order to understand South Africa's spiralling HIV/AIDS epidemic, the role of gender, sex and power must be examined. Women's experiences of living with HIV/AIDS and the stigma of HIV/AIDS are 'intensified because of their subordinate role in society' (Soskolne, 2003:1).

Traditional notions of female and male sexuality as illustrated earlier also play a key role in gendered constructions of stigma. It is asserted that gender differences and the double standards play a role in the construction of promiscuity and deviance; many sexual partners are a testament to a man's manhood, whereas women with many sexual partners are regarded negatively

as 'sluts' (Ratele & Shefer, 2002; Shefer et al., 2002). The association of HIV with promiscuity means that HIV positive women are faced with the stigma of being perceived as deviant or damaged (Lawless, Kippax & Crawford, 1996; Nack, 2000, 2002; Shefer et al., 2002) and having departed from the socially prescribed behaviour worthy of 'good women' (Lawless, Kippax & Crawford, 1996:1375).

HIV/AIDS is still associated with sexual misbehaviour and promiscuity. While it is almost universally acknowledged and accepted that men are much more likely to have had multiple sex partners, HIV-positive women face stigmatisation and are more likely than men to be blamed, stigmatised and abandoned by their families (Women's International Network News, 2001; UNAIDS/ WHO, 2002).

The continued silencing and stigmatisation of HIV/AIDS and STIs in South African communities is believed to further propagate unsafe sex practises. Men and women are afraid to reveal their status and risk infecting their partners. Studies report a perceived malicious promiscuity among those who are infected in order to 'punish' others (Simbayi et al., 1999). It is expected that women may resist disclosure and avoid the insistence of safe sex out of fear of male violence (Shefer, 2001).

Stigma may bring with it devastating mental, social, spiritual and economic consequences, and suffering for the person who is stigmatised. HIV/AIDS-related stigma and discrimination play into, and reinforce existing social stereotypes and

inequalities that make women seem inferior to men (UNAIDS/WHO, 2002). UNAIDS sponsored research in India and Uganda shows that women with HIV/AIDS may be doubly stigmatised both as 'women' and as 'people living with HIV/AIDS'. Black people living with HIV/AIDS find themselves stigmatised as both 'infected' and 'Black' and Black women would be further affected as 'women' (UNAIDS/WHO, 2002).

2.3. Experiences of Women living with HIV/AIDS

Lack of support and rejection for a woman living with HIV/AIDS from loved ones and friends are often a result of disclosure (Tallis, 1998). Disclosure of a person living with HIV/AIDS remains a difficult challenge, as there is concern about the consequences on themselves and families.

Women living with HIV/AIDS experience 'emotional, physical, social and spiritual' difficulties due to the often-negative responses that they are confronted with from family members, friends, health professionals and community members (Tallis, 1998:89). They have to deal with complex issues such as rejection by their partners, isolation from community members, financial constraints and psychological concerns such as low self-esteem and emotional insecurity (Auer, 1996). Fears centre on inevitable discrimination, negative social reactions, loss of employment, rejection from the family, expulsion from housing, isolation, avoidance and negative judgement should one choose to reveal your HIV status (Olley et al., 2003).

Women confronted with HIV infection will also have to deal with emotional and sexual challenges in the relationship with her partner, confront reproductive decisions and consequences, plan for the future of those children and confront the issue of disclosure to friends and family. Very often, this will have to take place without the support, emotionally and otherwise of the male partner (Van Deventer, Thacker, Bass & Arnold, 1999).

Women face different responses upon disclosure of their status and as a result, may prefer not to speak to anyone (Meursing et al., 1999; Vetten et al., 2001). Women are also known to adhere to and comply diligently with the demands of their partners, in some cases posing a threat to their health as an attempt to save the relationship (Burry et al., 1994; Meursing et al., 1999; Take Control, 2001b; Vetten et al., 2001).



2.3.1. Women's experiences of HIV Stigma

For women who are living with HIV/AIDS, the body is at the centre of political, social and religious struggles. The female body has been the subject of ridicule, adulation, envy, discrimination, abuse and stigma (Ackermann, 2001). Ignorance, prejudice, stereotypes, issues of power and dominance all conspire to stigmatise women living with HIV/AIDS (Ackermann, 2001).

Internationally, studies highlight women's experiences of HIV stigma. For example, in India, where a strong patriarchal society exists, it has been reported how women diagnosed as HIV positive experienced marginalisation and

discrimination, sometimes resulting in being severed from their families (Bharat & Aggleton, 1999). Similarly, in Hong Kong, Callaghan et al. (2002) conducted a study exploring perceived needs to elicit physical, psychosocial, health behaviour and informational needs of individuals living with HIV. The results of the study revealed that stigma, denial and exclusion were major sources of concern. Participants shared inability to disclose their status and feelings of isolation, having no one to talk to about their illness (Callaghan et al., 2002).

In South Africa, research revealed the main fears for women diagnosed with HIV positive to be fear of stigma, denial, exclusion and discrimination at a community, family and health personnel level (Shisana & Simbayi, 2002). In another South African study, Strebel (1993) reported that HIV/AIDS is depicted as 'a silent and invisible disease' (Strebel, 1993:194). Local researchers have asserted that if people are not comfortable with informing families close to them about their HIV status due to their fear of social rejection, behavioural change will remain a difficult task (Strebel, 1993; Tallis, 1998; Take Control, 2001).

In South African society, the Government has acknowledged that many women face 'triple oppression' on the grounds of race, class and gender, and has been making efforts to address this problem through education and skills development programs (Department of Health, 2006). The social restrictions faced by women mean that they are often powerless to enforce behaviour change when it comes to sexual relationships, even when they are aware of the risks involved in unprotected sex.

In contrast, a study in Uganda, evaluating counselling as well as medical and social service of The Aids Support Organisation (TASO) revealed that people's attitudes, knowledge and lifestyles displayed an acceptance of HIV (Kaleeba & Kallibala, 1997). According to the authors, this could be attributed to the National AIDS Control Programme, which was set up in 1986 following the first reported AIDS cases in Uganda. Radical change in the Ugandan mindset about HIV/AIDS has resulted in 90 percent of individuals revealing their status and a high level of acceptance of people living with HIV/AIDS by their families and the community (Kaleeba & Kallibala, 1997).

In another contrasting view a study on the relative impact of HIV/AIDS on thirty seven women's lives who were HIV-positive and who lived in a First World setting, Ciambone (2001) revealed that this sample of women did not consider HIV to be the most devastating event in their lives. Violence, mother-child separation and drug use were deemed to be more disruptive than HIV infection. Several factors, including race, social support and diagnosis, drug use and abuse were central to women's differential assessment of HIV in relation to other disruptive events (Ciambone, 2001). From this study it would emerge that HIV by itself was not totalling devastating, but when viewed in the context of its social, economic and family consequences, it could be debilitating.

It is asserted that women who are living with HIV/AIDS experience many forms of stigma and discrimination which is associated with characteristics which the larger society attributes to women. The attributed characteristics which include

the women's HIV infection, their gender, race, their perceived sexuality, and their socio-economic status are characteristics which intertwine and interact and according to Bunting (1996), they form a basis for stigma, separately and together. Women with HIV/AIDS have been forced to contend with multiple stigmas of being women, being members of racial minorities and being poor. Goffman (1963) posits that people think of a stigmatised person as not quite human. This assumed stigma or label of 'otherness' results in individuals acting out various types of discrimination, an action component of stigmatisation. It is argued that a stigma-theory is constructed, a rationale to explain the difference of an individual living with HIV/AIDS and to account for the danger he or she represents to others (Goffman, 1963). Discrimination towards women with HIV/AIDS can be traced back to the beginning history of the epidemic (Corea, 1992). In contrast, it is argued that the world only started to recognise the special threat that HIV/AIDS poses to women in the 1990s (Heagarty, 1992).

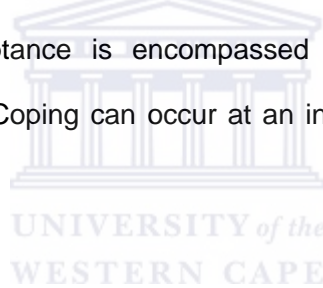
This compounding of HIV/AIDS related stigma by gender, race, sexuality and other factors is important, for our understanding of social responses and for the experiences of women.

Fears of the stigma attached to HIV/AIDS and discrimination, therefore constitute major barriers to accessing adequate care, support and treatment (UNAIDS, 2003). Orr & Patient (2004) posits that stigmatisation of people living with HIV is a major obstacle to dealing with HIV/AIDS effectively and that stigma poses the major barrier to people accessing resources and seeking forms of support.

2.3.2. Coping mechanisms used by women who are living with HIV/AIDS

Within a South African context, Black women living with HIV may be at a high risk of psychological problems given the realities of stressful living conditions, high unemployment, poverty, inadequate housing, high rates of crime and domestic violence (Olley et al., 2003). In addition stigma and disclosure have been described as major stressors for those diagnosed with HIV (Fleishman et al., 2000; Orr & Patient, 2004).

According to discussions about coping strategies during difficult times in one's life, a number of authors (for e.g. Barnett et al., 1992; Burry et al., 1992; Melnick, 2001) assert that the most effective coping strategy commonly utilised in stressful situations is positive self-expression based on internal or personal strengths. Social support and acceptance is encompassed when coping focuses on emotion and the problem. Coping can occur at an individual and organisational level (Melnick, 2001).



HIV/AIDS presents different symptoms according to the stages of the disease, therefore support and coping strategies will also vary (Dept. for International Development (DFID), 1998). It is imperative that the support and care needs should be determined according to the stage of the disease (Burry et al., 1992; DFID, 1998). Women are known to cope in various ways and this includes adopting a healthy lifestyle, practising safe sex or changing sexual behaviour and reducing their intake of alcohol and tobacco or refraining for its use entirely (DFID, 1998; Richardson, 1989).

It is widely argued that family members, representatives of religious communities, health-care providers and counsellors are important sources of psychological and spiritual support for people living with HIV/AIDS. Most people living with HIV/AIDS find the role of family support and social support systems a source of comfort and a positive structure to assist women living with HIV/AIDS to cope better (Parry, 1990; Barnett et al., 1992; UNAIDS, 2000a: 93).

Fear of the stigma attached to HIV/AIDS and discrimination, constitute major barriers to accessing adequate care, support and treatment (UNAIDS, 2003). It is argued that the stigmatisation of people living with HIV/AIDS is a major obstacle to dealing with HIV/AIDS effectively. Primarily stigma prevents people from accessing resources and seeking necessary forms of support (Orr & Patient, 2004).

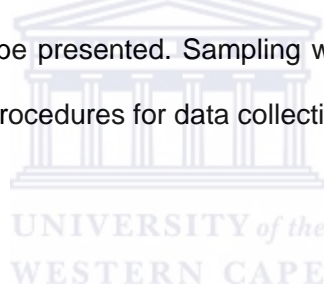
2.4. Conclusion

This chapter, in summary, has presented a review of studies towards developing a deeper understanding of the experiences of women who are living with HIV/AIDS in the context of stigma. This chapter demonstrated the stigmatisation processes, how these are gendered, and the impact of these on women who are living with HIV/AIDS. Probing beyond the statistics, it appears that women's vulnerability to HIV/AIDS occurs on a variety of levels, biological, social, individual and maternal. Women who have little or no education and who live in traditional patriarchal relationships, have limited access to information on

HIV/AIDS, and generally lack the skills and the power needed to negotiate safer sex (Tallis, 1998).

HIV/AIDS has devastating consequences for *all* South Africans, regardless of age, race or class or HIV status. The AIDS pandemic is particularly perilous for South African women. While it is cutting a deadly swathe across the educated classes in the 20 to 40 age group, its greatest impact is on the most vulnerable members of society, the poor, the marginalized and the displaced (Karim, 1998). This makes HIV/AIDS a crisis for women, in particular poor and marginalised women.

In Chapter 3 the research design of the study will be examined. The methodology employed in this study will be presented. Sampling will be discussed as well as the ethical considerations, procedures for data collection and self-reflexivity.



CHAPTER 3

RESEARCH METHODOLOGY

Inherent within the focus of this study is the assumption that stigma is experienced by women who are living with HIV/AIDS in contemporary South African communities. In an attempt to enhance the profundity of the study, feminist qualitative methods were used, but it is also arguably the most appropriate methodology for a study focussing on women's experiences and through a feminist/gendered lens. This chapter outlines the process and methods used to conduct the study. Furthermore, the chapter deals with the framework of the study, the procedures in selecting the participants and setting up of the focus groups and the methods used to analyse the data.

3.1. Methodological Framework

Feminist Qualitative Research

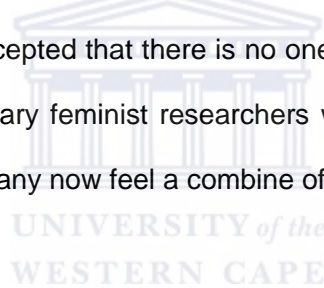
Burman (1991:124) defines feminist research as a 'commitment to a specific, feminist epistemology; that is theoretical and political analysis that critiques dominant conceptions of knowledge, and poses questions about the gendered orientation of, and criteria for knowledge'. In *Researching Women's Lives from a Feminist Perspective* (1991), Purvis asserts that the earliest definitions of feminist research centred on the creation of knowledge about women through research with women. The link between research and action/activism was tenuous, critical reflection on personal experience and awareness of differences between women muted. There is however a strong body of feminist research and

work on feminist research methodologies which does emphasise the link between research and action/activism. Whilst much feminist research rightly focuses on women, on creating knowledge about women's experiences, if our concern is to understand women's oppression we need to target our attention on ways it is structured and reproduced. Feminist research focuses on how women's lives are constrained by the actions of men individually and collectively and the strategies girls and women find to resist, challenge and subvert the status quo. Studying women's lives as a feminist means that male dominance, masculinity and men are always part of, and will be challenged by the research (Purvis, 1991).

Feminist qualitative researchers employ various strategies of enquiry that will differ depending on the purpose of the study, the nature of the research question and the skills and resources available to the research (Morse, 1994; Rubin & Rubin, 1995). It can be argued that there are many research methods prescribed by feminist methodologies or research procedures (Kelly, Burton and Regan, 1994).

This research project will use focus group discussions as the method of data collection. What constitutes feminist methods depends on how the piece of research is evaluated in relation to its purposes or goals and what it seeks to achieve (Burman, 1991). What most feminist research has in common is the goal to create social change. In an attempt to understand the context or setting of my female participants, this research method is socially relevant (Burman, 1991).

Some researchers of Second Wave feminist scholarship argued that feminism has a method of conducting social research, which is specific to it. These arguments advocated and defended a qualitative approach to understanding women's lives as against quantitative methods of enquiry (Maynard & Purvis, 1994; Naples, 1996). Quantitative research, in particular surveys and questionnaires, were seen to represent a 'masculinist' form of knowing, the emphasis being on the detachment of the researcher (Maynard & Purvis, 1994; Devault, 1999). The use of qualitative methods, by contrast, focuses more on the subjective experiences and meanings of those being researched and is regarded as being more appropriate for the kinds of knowledge that feminists wish to make available. It is seen to be more in keeping with the politics of doing research as a feminist (Griffin, 1996; Maynard & Purvis, 1994). Nowadays however it has been clearly argued and most accepted that there is no one feminist research method. There are many contemporary feminist researchers who are not so rejecting of quantitative methods and many now feel a combine of both methods is useful.



The terms 'feminist' and 'women's' are often used interchangeably in literature and although a feminist approach is almost a definitional one which commences with women's experiences, it must be noted that many women would not define themselves as feminists and would not necessarily argue with accounts of the social world generated from a feminist stance. Feminist researchers assert and conclude that there is no one answer to the question about what feminist research is. Many contested issues of method, methodology and epistemology remain (Maynard & Purvis, 1994).

In conclusion, while the terrain of feminist methodology is contested, there are some key concepts and goals that most feminist researchers have in common. These commonalities include the following: 1) research should be socially relevant; 2) research is never neutral, objective or unbiased; 3) the importance of the dynamics of research and therefore of self-reflexivity and acknowledgement of the researcher.

3.2. Aims of the Research

Against the above-mentioned framework, the broad research aims of this study are to:

- Explore the social, emotional, physical and spiritual experiences of a group of women living with HIV/AIDS within two identified communities;
- Explore whether participants experience stigma and gendered stigma relating to their HIV status;
- Explore whether their experiences of living with HIV is complicated by social responses to their status, in particular stigma;
- Explore HIV/AIDS interventions and coping mechanisms for women living with HIV/AIDS.

3.3. Procedures

3.3.1. Recruitment of Research Participants

Participants for this study were identified through contact with key individuals and community organisations in two specific communities, Mitchells Plain and

Guguletu. The researcher was requested to conduct the focus groups within these areas as part of the requirements for the larger research project, which was being conducted by PennState University, Human Science Research Council and University of the Western Cape. This sampling method was purposive as a particular group of women was targeted. Participants who met the criteria, that is, being a woman of any age who was living with HIV/AIDS, were subsequently included through a snowballing method as the need for participants was made known in the communities by word of mouth. This involved telephonic communication, followed by a meeting. A meeting with a key person at the prospective venues was held to establish the recruitment of the participants and the date for the focus group discussions. This procedure was necessary to obtain permission and support for the project. I was in possession of a letter from the Human Science Research Council, which outlined the purpose of the study and was an endeavour to assist me to gain entry into the community. The target population of this study was women of any age, who are living with HIV/AIDS in the two identified areas.

During the research recruitment process one of the challenges was that a few prospective participants who were approached and who met the study criteria, failed to keep their appointment. Some of them gave no explanation for their absence while others tacitly stated that after consideration they decided not to be involved in the study. The key contact person at this particular venue communicated that these women are amongst many others who do not return for treatment after they have been informed of their status, for fear of disclosure to

their family and friends. A total of 36 participants were interviewed in the course of 6 focus groups.

3.3.2. Mitchells Plain

Mitchells Plain was historically created for 'so called', coloured people who were removed from District Six in Cape Town in 1976. It is situated at the margins of the greater Cape Town Metropole. The Mitchells Plain community was supposed to service the city of Cape Town with cheap labour force. Mitchells Plain is situated about 5 kilometres from Khayelitsha and 30 kilometres out of Cape Town with about 1,5 million inhabitants, it is the second biggest township in Cape Town and is currently fairly well established. A major strength of the area is that most people work for themselves by having fresh vegetable and fruit outlets and fish, which is a very successful market in Cape Town. The poor clustered housing and the painful experience of being forcefully removed contributed to a high crime rate. Originally, the community was left with no infrastructure and no shopping centres, nor was public transport provided. On the other hand, Mitchells Plain has been declared as a node for the Presidential Urban Strategy due to having one of the highest crime rates in the country. Mitchells Plain has a huge problem of gangsterism which goes hand-in-hand with all sorts of crime like murder, drug trafficking, rapes, hi-jackings, robberies and other related crimes. Some of the other challenges of the community are high rates of unemployment, teen pregnancies, alcohol abuse in shebeens, and early school dropout. Women and children are sometimes caught in gang crossfire. Gender inequality and

gender-based violence remain rife in Mitchells Plain.

http://www.umac.org.za/Areas/areas_maps_detail.asp?areaID=14

3.3.3. Guguletu

The population size of Guguletu is about 800 000 with youth in the majority. The street names NY1, NY2 etc. short for 'Native Yards', and the shortage of housing and facilities recall the years when black Africans in Cape Town were treated as outsiders from the Eastern Cape. Ten or more people may share a small two-roomed 'matchbox' house and others live in bungalows in back yards. One under-resourced police station, one under-resourced day hospital, a library and a few multi-purpose centres, a technical college, crowded schools and many churches serve 'Gugs'. The people of the area travel to work every day, which is in town, the suburbs and the industrial areas. Many are unable to find formal employment. It is estimated that half of the workforce are self-employed; in spaza shops, hawkers, hairdressers, undertakers, backyard mechanics, taverns, taxis, tailors, etc. Many are jobseekers. While the atmosphere on the streets is lively, many struggle to survive in poverty. Crime is rife in the area especially hijacking, murder, mugging, armed robbery and rape, with the youth dominating the activities. Alcohol and drug abuse, family violence and child abuse are also serious problems.

http://www.umac.org.za/Areas/areas_maps_detail.asp?areaID=11

3.3.4 Demographic Information

A demographic questionnaire (See Appendix C) was designed to gather demographic data (See Table 1 below) on the participants' lives. The women ranged in age from 18 to 52. Three focus groups were held in Mitchells Plain and three in Guguletu. The size of each group varied from 6 to 8 participants.

Table 1: *Ages of Participants*

Age Group	Number of Participants
18-25	10
26-35	13
36-45	9
46-52	4
Total Number of Participants	36

Eight women have completed Grade 12 in High School, four completed Grade 11, eight completed Grades 10 and, 6 and 3 women completed Grades 9 and 8 respectively. One participant was a student in Grade 11 and the remaining participants dropped out of primary school from Grades 6, 5 and 4. The table below reflects the employment status of the participants.

Table 2: *Employment status of Participants*

Employment Status	Number of Participants
Student	1
Housewife	2
Unpaid Volunteer	3
Unemployed	22
Employed	8
Total Participants	36

It is evident that the majority of participants were unemployed (79%). Of the 8 participants who were employed, 7 were earning a monthly salary of less than R2 000.00 while 1 participant earned a monthly salary in excess of R4 000.00.

3.3.5 Focus Group Discussions

In line with the assertion of Krueger (1988) that focus groups involve small groups of people with particular characteristics convened for a focused discussion of a particular topic, I conducted six focus groups of only 6-8 participants in each.

Wilkinson (1998) argues that group interviews of various kinds (generically designed focus groups), offer an important opportunity to explore issues relevant to the person in context. This method, according to Wilkinson (1998) provides a valuable methodological tool for feminist psychology and for feminist research more generally. Wilkinson (1998) asserts that the relative power possessed by research participants at the data collection stage of focus groups, compared with interviews, is not merely an ethical issue but it also improves the quality of the data. Strebel (1995) asserts that the qualitative method of focus groups originated in market research but has been used increasingly in social research and health education. It has been utilised in AIDS research generally, and specifically in research with women (Duke & Omi, 1991; Flaskerud & Rush, 1989; Schoepf, 1993; Strebel, 1995).

It is argued that focus group discussions are shaped by multiple social contexts (the associational; status, especially gender; conversational and relational). Researchers often ignore this fact. These processes limit the usefulness of focus groups as a tool for understanding individual thoughts, feelings, or experiences. However, they make focus groups an excellent site for analysing the processes

of social interaction (Hollander, 2004). Focus groups can address ethical issues about the power of the researcher in the data collection process; can yield high quality, interactive data, and can offer a route to studying the person in the context of a social world (Denzin & Lincoln, 2000).

This method will enable the researcher to gather sensitive data required for understanding the circumstances of the target communities and their perceptions and viewpoints in terms of the topic of research. Some of the studies that have been conducted on focus groups show that group participants find the experience more gratifying and stimulating than individual interviews (Morgan, 1998; Wilkinson, 1998).

Semi-structured interview questions were used to allow participants to engage in a process of exchange of information and experiences (See Appendix A). The term 'stigma' was avoided in the questions, which were formulated to explore the experiences and reported social responses to women who are living with HIV/AIDS. Interviews followed a guideline, yet there was ample room for participants to elaborate or to introduce issues they considered relevant.

3.3.6. Procedures for Data Collection

I confirmed telephonically the arrangements for the focus groups and proceeded to the venues on the scheduled day and time. Two female research assistants with post-graduate qualifications and focus group facilitation skills, assisted the researcher with the focus groups. The mother tongue of the assistant for the

Guguletu area was Xhosa as the groups were conducted in Xhosa. The group in Mitchells Plain was conducted in English and Afrikaans and the assistant was someone fully conversant with both languages. The duration of the discussions was approximately one hour. All the discussions were audio taped and the participants showed ease throughout the discussions and were not unnerved by the tape recorder.

I thanked the participants for attending the group, explained the reason and purpose for the study and with the help of the assistant, guided the participants with the completion of the consent form (Appendix B) and the form requesting personal details which was required for demographic information (Appendix C).

I purposefully attended to these logistics before the discussions, as I wanted to be sensitive to the participants who may have needed time to compose themselves after partaking in a discussion of such a sensitive nature. I did not want to appear to be transactional in expecting them to complete various forms.

After the completion of the forms, I welcomed everyone and again thanked them for being willing to participate. I introduced myself officially as well as the research assistant. The research assistant sketched a diagram of the seating arrangements of the group together with field notes during the discussions. I found it very useful to inform the group that the opinions of all the participants were important for the research project and were valued. In an attempt to avoid people feeling pressurised to agree with others, I emphasised that there could be

no 'right' or 'wrong' answers to my questions. I carefully followed the suggestion of Sterk (1989) that it is important to bear in mind that too much knowledge might be seen as threatening. I interpreted this to mean that while I wanted to know something about the participants I was studying, too much knowledge might be seen as threatening. I therefore allowed the participants to lead the discussion after I posed each question. At the end of the discussions, I again thanked everyone individually for their participation while exchanging a hug and R50.00. This amount was given to participants as a token of appreciation for their time and financial assistance they incurred with travelling costs. While participants were not informed of this arrangement prior to the interview, it is standard practise and in line with the policy of the Human Science Research Council who formed part of the collaboration for the completion of the broader study.

3.4. Data Analysis

The process of data analysis involved structuring and bringing logical order to the vast volume of data collected. The data was first transcribed verbatim from the tape recordings onto a computer. An assigned transcriber assisted with the translation and transcription of the Xhosa groups, which I checked against my field notes. Transcribing and analysing the recorded discussions were conducted with the help of qualitative data processing software, the Nvivo package. It is argued that no single software package can be made to perform qualitative data analysis in and of itself. The appropriate use of software depends on appreciation of the kind of data being analysed and of the analytic purchase the researcher wants to obtain on those data (Coffey & Atkinson, 1996).

I organised and prepared the data for analysis which involved transcribing the interviews while referring to the field notes. I read through the data three times to obtain a general sense of the information and to reflect on its overall meaning. I pondered on the general ideas and the tone of the ideas that were reflected by the participants. I commenced the analysis with a coding process. According to Rossman & Rallis (1998:171), coding is the process of organising the material into 'chunks' before bringing meaning to those 'chunks'. It involves organising text data into categories and labelling those categories with a term, a term often based in the actual language of the participant called an *in vivo* term (Cresswell, 2003). I used the coding to generate a number of themes. These themes are the ones that appear as major findings in the study and appear under separate headings in the findings section.

According to Smith (1995), there is no one correct way to employ qualitative thematic analysis. Smith (1995) asserts that each project creates the appropriate manner for the employment of thematic analysis. Researchers should give meaning to the participant's interview and engage in an 'interpretative relationship with the transcription' (Smith, 1995:18). Themes, according to Ryan & Bernard (2000:780), are seen as '.... abstract constructs investigators identify before, during and after data collection'.

3.5. Ethical Considerations

In line with the code of ethics, participants were assured of confidentiality and anonymity. They were advised that their names would not be used during the

focus group discussions. A number would represent them instead. All identifying data will be altered during transcriptions. Participants signed a consent form (See Appendix 4) after it was read aloud and explained by the researcher. The researcher has an obligation to respect the rights, needs, values and desires of the participants. It is argued that there are limitations to informed consent. A major element in the ASA Proposed Code of Ethics (1988) is the concept of 'informed consent', by which the subjects of research have the right to be informed that they are being researched and also about the nature of the research. The informed consent form also states that the subjects may withdraw from the research project at any time. It is often assumed that the subjects understand the intent of the form, which they are expected to sign and return to the researcher before the research takes place. The subjects are assumed to have enough knowledge to understand the research jargon and the complexities of the research, and to be aware of their freedom to choose to participate or not (Goduka 1990). According to Thorne (1980), informed consent entails three dimensions: knowledgeability, voluntary participation, and competent choice.

3.6. Self-reflexivity

According to Lincoln & Guba (2000), reflexivity forces us to come to terms not only with our choice of research problem and with those with whom we engage in the research process, but also with ourselves and with the multiple identities that represent the fluid self in the research setting. The authors argue that we not only bring the self to the research field, we also create the self in the field (Lincoln & Guba, 2000).

Before and after the interview I engaged in preamble and informal talk with the participants. I believe that this contact impacted positively on the participation in the research process because there was evidence of elements that make woman-to-woman interviews more comfortable. My gender, my skill in conducting support groups and group therapy sessions for grieving people, as well as my professional status as a university student facilitated rapport and led to a tacit understanding that I was welcome. This made the interview process relatively easy. These elements operated separately but facilitated the research process positively. As a researcher I was constantly aware of how my values, attitudes and perceptions influenced the research process, from the formation of the research questions, through the data collection stage, to the ways in which the data was analysed and explained (Abbott & Wallace, 1990:27). Although I am black and a woman, and therefore share some aspects of social identity with the participants, I was at the mercy of research participants who could choose to respond in whatever manner they desired. I took the responsibility to negotiate a relationship of mutual respect and trust within the timeframe I had.

Although there were clearly power differences between myself as a middle class postgraduate student who is not living with HIV/AIDS, I believe this did not impact negatively on the process. A group of four women researchers Green, Barbour, Bernard & Kitzinger (1993) who were involved in four different studies about HIV-related risk behaviours alluded to a shift of balance of power during data collection, simply by virtue of the numbers of research participants, such that, in

a focus group situation, research participants have more control over the interaction than the researcher.

In contrast to this belief, I did not find any evidence of this type of shift in the balance of power during the research process. I was entrusted with a huge amount of information about the experiences of the women I studied and I did not feel that they expected a lot from me in terms of how I proposed to present the image and traditions of their world to others. There was no indication that they expected me to keep in touch with them in between research visits and even after the research project was completed. My shared racial background proved to work to my advantage in establishing a relaxed and comfortable environment, which the participants found meaningful. After conducting the first focus group I felt emotionally drained as I absorbed the painful experiences of the participants. I drew strength from the debriefing shared by the research assistant and palpably each subsequent focus group was conducted with more ease as I became skilled in separating myself emotionally from the discussion.

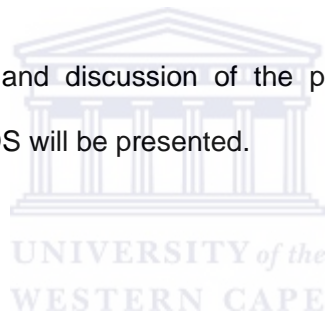
Studying the lives of these women who are living with HIV/AIDS has made me more aware of the fact that every researcher is affected by the work he or she does. I found it difficult to remain neutral and uninvolved. I recognised the fact that as a researcher I was a part of the community I was studying. As a result of this sensitive topic researched, I have pondered on and asked myself the following questions many times: How am I affected by HIV/AIDS? How am I a

part of the problem (aiding the impact of stigma)? How can I become a part of the solution?

I believe that this experience has challenged me to consciously make a difference in the struggle against HIV/AIDS and particularly stigma and I have subsequently become actively involved in doing that.

In summary, this chapter has presented the research design of the study. Research methodologies were explored and it was argued that a feminist qualitative method was most suitable for the study. Ethical issues were discussed and the research process explained in detail.

In Chapter 4 an analysis and discussion of the participants' experiences of stigma in living with HIV/AIDS will be presented.



CHAPTER 4

DATA ANALYSIS AND RESEARCH FINDINGS

4.1. Introduction

This chapter is an analysis of the data in an attempt to gain an understanding of the experiences and meanings of stigma for women who are living with HIV/AIDS. This chapter presents a discussion of the research findings in their original form as they emerged from the data. The first section examines the knowledge and perceptions women have of HIV/AIDS, and the impact that this had on their personal experiences. The second section will look at the women's subjection to the perceived reactions to women living with HIV and the impact this had on their relationships. The third section examines gender inequality with respect to perceptions and experiences of those living with HIV and is a discussion of how women and men are treated differently. The final section will focus on the interventions and mechanisms participants report in their attempts to protect themselves against the negative responses they have experienced. A summary of the themes, which are further divided into sub-themes, is:

- 1) Perceptions of HIV/AIDS
- 2) The impact of HIV/AIDS on relationships
- 3) Gender Inequality
- 4) Interventions and mechanisms for coping

4.2. Perceptions of HIV/AIDS

According to the authors of the S.A. National HIV Prevalence, HIV Incidence, Behaviour & Communication Survey (2005) perception, knowledge, and attitudes of HIV/AIDS are imperative precursors for behavioural responses to the disease. It is argued that while surveys are useful towards tracking general levels of knowledge in key areas, it is recognised that the knowledge necessary to address HIV/AIDS is complex, and basic knowledge is not necessarily sufficient towards addressing response (Shisana et al., 2005).

These findings reveal that attitudes and stigma towards PLWHA are strongly linked with knowledge of HIV/AIDS. The Nelson Mandela/HSRC Study of HIV/AIDS (2002) argues that better knowledge of HIV/AIDS has been shown to have a positive relationship to prevention behaviours and positive attitudes to people with HIV/AIDS. The authors argue that this does not imply that knowledge is a sufficient condition of behaviour changes and positive attitudes, but it is necessary (Shisana & Simbayi, 2002).

This present study revealed a lack of clarity about whether AIDS is curable, as well as a lack of knowledge about HIV/AIDS.

...it's here to stay because so far there's no cure for it if you said you are HIV they take it like you are a outcast.

A participant who disclosed her status the same day she tested positive reveals the confusion she experienced as she admits her lack of knowledge about HIV/AIDS.

... the same day. They said I was lying, after that I went home. At home I stayed for a while got into my bedroom and slept. I thought a lot I have children. A person with AIDS no man, HIV I do not have AIDS. Like I did not know much about HIV and now I have that thing that HIV is a virus it is not AIDS, so if I treat this thing it will remain a virus never become AIDS. A person with HIV can die so if I can die and leave these children what would I do?

Richardson (1989) suggests that women living with HIV/AIDS should be made aware of how HIV infection occurs as feelings of depression may progress their status. They should be made to understand and have access to accurate information rather than myths or assumptions (Long et al., 1996). This was confirmed in what was said by this participant:

I would say that if the community can call a meeting of all the people from different streets of the community and be educated about HIV and AIDS. They should cover things like, people wont be infected by just speaking, drinking from the same cup, they should know that people who are HIV positive live a normal life just like anybody else, the only difference is that they are HIV positive....

With regard to key knowledge of prevention, a participant shared sadly how prior knowledge that she had equipped herself with, did not prevent her from being raped.

The day it happened to me it was like it's not me, it never happened to me because I always thought of the knowledge I had of HIV. For me it was like I thought I will never have HIV because of the knowledge I had, the booklets and you know you must never have unprotected sex and sharing needles. But the day I was raped and the day I feared I was HIV positive and actually uhmm I didn't know that time I didn't know how to deal with it. 'Cos it 's for me like how can I say, it's a promise I made to myself and I told myself I will be careful and I know how you get HIV & AIDS and I will be very careful. I will be very preventive but uhmm by being very preventive I did get it and I'm being forced to live with the virus.

4.2.1 Negative Fears expressed as a result of Beliefs of HIV/AIDS

As has been reported in other studies for e.g. Rohleder (2004), for many women, having HIV/AIDS was constructed as a death sentence and this caused much anxiety as thoughts of death were constantly on their minds. These responses reveal that participants have accepted dominant constructions of HIV/AIDS as a disease of gloom.

My view about HIV and AIDS is that, the most thing is death.

When you are with people and people say yhu-uu and so and so has got AIDS and that makes me feel that I'm going to die because I have it and you become scared and even if you are happy today but you might die tomorrow.....

It's a horrible disease, horrible. Like on TV you see somebody dying. You just cry and you know that the day will come when you are going to die.

What I understand about HIV is that it is death, it is that I will die because it is not something that can be cured and you get better.

For me I already see a coffin in my mind, and you do not feel comfortable like you can not talk in front of people, it is like this thing is on your back, it is sticking to you.

I also think about death it is the first thing I think about, and then I think about what if I was to die now what would I do? It is like you think about death all the time.

I think about death when we talk about HIV/AIDS

Even though some participants did not express their views by using the words death or dying, their immediate concerns raised about their children is evidence that they too equated living with HIV/AIDS as a death sentence.

I have fears that I have to leave my children behind. How are they going to survive? I always think about the virus.

I also think about my two kids. They are still young.

My daughter she knows that I'm HIV and ever since she has changed and she's not the one that we know. She's 15 years old. She has changed she's not the one that I know. Yes she is affected knowing that her mother's gonna die.

...you think about your mother, you think about your children and your anger and, and you think about those things. Is she gonna be able to look after my child if one day I die, you know, so that's how it is.

.... I have a small child I think about who will look after this child should I die and like other people have died so the minute you have a friend that dies you become very scared, you think I wonder if I will wake up tomorrow.

A participant who spoke positively to herself in an attempt to deal with the knowledge of her HIV positive diagnosis, shared how in spite of coming to terms with living with HIV in a positive way herself, she is unable to deal with the anxiety relating to her children. She spoke with a deep sense of compassion as she related her self-talk.

...after that I went home at home I stayed for a while got into my bedroom and slept. I thought a lot. I have children. A person with AIDS, no man HIV I do not have AIDS, like I did not know much about HIV and now I have that thing that HIV is a virus it is not AIDS, so if I treat this thing it will remain a virus never become AIDS that is what I tell myself. I did not stress myself with this thing it is now that I am stressing myself about my children.

4.2.2 Positive views expressed as a result of Beliefs of HIV/AIDS

There was however also some resistance to the construction of HIV/AIDS as a 'death sentence' through attempts to reconstruct the experience differently. Some participants when asked about their views and understanding of HIV/AIDS expressed the desire to see HIV/AIDS being viewed positively.

To me, when we speak about this sickness I just think that everyone should take care of him/her self, even though we cannot say that he does not care but he/she should stick to the condom at all the time.

I want to say that when people hear about HIV and AIDS they must not think about death because there is still so many years ahead of you, there is treatment and people should take treatment so that they can live longer.

A participant who remained silent for a very long time and when prompted a second time to respond, spoke of her positive feelings. This participant is a member of a support group, which has proved to have a positive effect on her well-being and as a result on her perceptions and experiences of living with HIV/AIDS. During the discussion at a later stage, she spoke enthusiastically about the group dynamics in the support group and this appears to have added value to her life and contributed to the meaning she gave to the virus.

What I would say is that when I think of this virus, I feel positive, so the thing that you should think about is your future don't think about staying indoors and not wanting people to visit you because you are HIV positive. You know that people will go around and gossip about you but you should tell yourself that you still the person you were before and there is nothing that can change me.

4.3. The Impact of HIV/AIDS on relationships

The participants spoke of the experiences they had as a result of the impact on their relationships with their partners, spouses, family members and the community after receiving confirmation of their HIV status. Across the world the global epidemic of HIV/AIDS has shown itself capable of triggering responses of compassion, empathy and support, bringing out the best in people in the community and their families (Dube, 2003). On the other hand, many studies have shown negative and rejecting responses from families and communities (Hackl et al., 1997; Hough, Brumitt, Templin, Saltz & Mood, 2003). These findings reveal that the disease is also associated with stigma, repression and discrimination, as individuals living with HIV/AIDS have been rejected by their families, loved ones, communities and those responsible for caring and treating PLWHA.

4.3.1. Familial context

The familial context as a context of disclosure has been well researched (Kahn, 2004). In western contexts, nuclear family members (e.g. parents, siblings, children) are viewed as some of the most likely potential recipients of disclosure of HIV status, while the extended family (such as grand-parents or in-laws) are far less likely to be considered high-priority disclosure recipients (Greene et al., 2003). However, family 'is a broad term, varying in specificity by culture' (Greene et al., 2003:72). It is important to note that black familial structures do not always conform to western notions of the family as an urban self-contained nuclear unit.

In the majority of developing countries, families are the primary caregivers to sick members. There is clear evidence of the importance of the role that the family plays in providing support and care for people living with HIV/AIDS. The findings of this study reveal however, that not all family response is positive. Members of the family living with HIV/AIDS can find themselves stigmatised and discriminated against within the home. The participants of this study who chose a family member to disclose their status spoke to either an aunt or uncle, husband or mother. Most of the participants who disclosed to a family member turned to their mother and it is evident from the findings that they received more care and support from them than from any other family member.

Well for me at that point in time my mommy ever since I found out that I'm pregnant, she's been supporting, she's been caring now and we sort of had a close relationship. It wasn't always that I could go to her but at that point of time

she was there and she was the nearest one that I could count on in telling my situation.

When I found out I was HIV positive my mommy was very supportive by coming with me to find out more about HIV and AIDS and how she can assist me with whatever things I need.

A participant who felt confident that she could trust her mother, motivated by her fear of dying within a week of learning of her positive status was faced with having to leave home after her mother shared her status with her father. Even though she had a close relationship with both her parents, her father's reaction was very harsh and has caused this participant much pain and feelings of depression.

....I trusted my mom. And I just think she must be the first person to know these things and I was thinking that I'm going to die within that week. I was scared if she can find out when I'm in the coffin. I am close to my father more than to my mother. I wanted to tell my father. Then my mother asked me are you sure you want to tell him and I said yah. I want to tell him and I know that my father likes me more than anyone in the family. So my mother said OK if you really want to lose your family and I said no I don't want to lose my family. Then my mother told my father. I didn't know the day that she told him.but one afternoon he was sitting with his friends and I came in and I sat down and he was looking at me and I didn't know because my mother didn't tell me I told your father about this thing. Then what happened is I just looked at him and said, 'what's wrong why are you looking at me like that?' and I also ... And everyone was looking at me. And he said 'I don't want to see you anymore because you have AIDS'.

This participant continued to describe the humiliation and shame she suffered as the person she felt closest to broke her trust and openly disclosed her status. She clearly had feelings of rejection as she suffered this abandonment from her family members.

And I feel like the ground can open and swallow me because his friends were there. Everyone was there and he was shouting and he started throwing my clothes out. He said because I have AIDS I'm going to infect all of them. And I was crying because I didn't know what to do because everyone, the neighbours was out. He was shouting and saying she's got AIDS and my mother was crying. My sisters were crying and I didn't want to go out. He pushed me to go out. My mother was very angry and she phoned my sister in P.E. And she was angry and said I must come and live with her. And from that day I suffered from depression

because I was thinking because my father threw me out and I thought I was going to die and I didn't have hope.

Another participant was callously removed from her place of accommodation when an aunt with whom she was living learnt about her positive status. She shares her experiences.

I had experiences about it. I am living for 14 years with other people and I live with other people and I have 2 children. The baby is also HIV positive and my aunty found out. And my aunty rejected me and my aunty didn't want me to stay there. She scolded me because I must leave. When people don't want to share it's painful to think your own family rejects you and outside people accept you as you are. She threw my wendy house down and she scolded me.

Participants continued to speak with difficulty about the negative ways they were treated in the family and how this made them feel:

My family broke up. My children didn't want anything to do with me. They didn't want to live with me any longer. Now I have people looking after me. People from Congo is looking now after me.

I got sick in prison. My parents wanted nothing to do with me. My nieces helped me. When my father died my mother became supportive. But my families still speak bad about me. I cry a lot.

A participant who confidently started relating her experience started out by mentioning that no one in her family treated her differently because of her status. She spoke after many of the participants in the group expressed their pain after they related how they had been treated badly by their family members. As this participant became aware of what she had just said, she suddenly realised that she had in fact been treated differently and, almost in an attempt to justify her family's behaviour, ascribed it to lack of education.

From my side of view first my uncle and my aunt was HIV positive. Nobody treated me different. It was only my sister that treated me different and a brother of mine. My youngest brother. Because he didn't know what the virus was and he

didn't study about it and like he didn't take note on school what he's doing. Then he was like he used to say you HIV positive or like just shout at me.

Participants spoke about the restrictions that were placed on them by family members.

They stress the person, they do not give them time, they do not treat them well. They want to hide the person. They do not wash the person. They gossip, talk about, you can hear the family talking about you to other people sometimes lies and you do not live right.

Sometimes they separate your plates and your spoons.

They don't want you to cook for them. They feel you are sleeping around. You've got many boyfriends.

Sometimes they say you are going to infect them and they just chuck you out and say no you are going to infect us and not knowing maybe how you got infected. They say you have many partners maybe you are cheating. They don't want to share anything, they don't want your food and other stuff.

4.3.2. Intimate Partners

Women gave accounts that illustrate the powerful and often destructive effect that disclosure can have in the context of intimate relationships, and the difficulty facing HIV positive women in finding a male partner willing to accept their positive status or acknowledge his role.

Participants spoke of how their partners rejected them after learning of their status. Even though this was not clearly stated it is evident that disclosure to a partner poses a risk to the relationship. In these cases the relationship ended after disclosure.

I told my boyfriend. He was supportive but now we not together. He was first worried about the baby and asked how is the baby. Is the baby OK? But now he is not worried. He left me.

....I disclosed to him telling him about my situation He said this thing came with you and I am not going to be there, that is all.

.....the moment you tell your boyfriend you will never see him again.

Some participants indicated their fear of losing their partners through revealing their status. A participant who decided to share the news of her status in a different way, elaborates her experience:

For me I never told the father of my son. I went on a TV program called BEAT IT from TAC. Since then I haven't seen him again.

The participants reveal that women seem to accept the negative responses from their partners passively. It is evident that inherent blame is internalised after their partners have deserted them. Women don't appear to be outraged especially when men's behaviour results in their partner's infection. As has been reported (Nashandi, 2002) women are blamed for their own infection and that of their partners. As a result women find themselves ostracised, rejected and abandoned. The participants in this study confirms the argument that there is no shared responsibility created or encouraged in public messages about HIV/AIDS but that women are by nature made accountable for the disease (Richardson, 1989; Burry et al., 1992).

4.3.3. Broader Community Context

With respect to the larger community, responses to disclosure ranged from support in some instances, to rejection in most cases. Participants emphasised variation in community attitudes towards HIV/AIDS. A participant singled out her own community as one that is more inclined to stigmatise. She emphasised that her community is a 'difficult' one for a person who has been diagnosed with HIV, because of the lack of

education around HIV/AIDS. This opinion seemed common amongst participants of this coloured community however, the focus groups held amongst black participants reported the same response.

Socially, HIV/AIDS affects relationships at all levels and the findings highlight its impact on all aspects of life.

There is like uhmmm no support because in our Coloured areas the people are so illiterate regarding HIV/AIDS. It is. And once you have it they so shocked that I tell my sister, my sister tells her friend and when you walking down the street everyone is looking at you staring at you

HIV and AIDS is discrimination within our community. I was being abused and discriminated against since 1995

Participants gave some insight into general community perceptions and attitudes towards HIV/AIDS and an account of community reactions towards wearing T-shirts advocating HIV.

.....in my friends funeral there were guys there that had not seen each other and wanted to shake hands with the people attending the funeral but they wanted to know from some members of the support group why they were wearing the HIV positive T-shirts. They were told, man don't you know that we live with HIV and the person said, hey man you also have this thing. The person then tried to wipe their hand because they had shook hands with the person. They were disgusted by this person with HIV and did not even want to speak to the person after that. It is difficult for them to even sit close to you if you have this thing. There are still people like that.

Other extracts from participants suggest that stigmatisation relating to their status was extended to their children, which was equally painful and traumatic for these women.

When you come upfront among those who are HIV negative you find rejection for children. You find that adults do not want their children to play with yours. It is very painful this thing. You find that you are positive and parents do not want their children to play with yours.

Participants strongly held the view that disclosure implicated a PLWHA and suggested that it evidently proved to be a risk that resulted in possible stigmatisation and discrimination in the community.

I disclosed myself the very same day I came from the clinic. But there was another neighbour of mine. Every time when she come yessis 'you are HIV'. You see that's why the other people they keep it a secret. I thought I was wise telling the people but I was very stupid.

4.4. HIV/AIDS and Gendered Stigma

These findings reflect on the position of women in relation to HIV/AIDS in the South African context and has brought to light evidence that the role of gender was acknowledged as a specific factor in shaping experiences of HIV/AIDS stigma and support, and as such, is a critical point that emanates from the study. The participants' related experiences reveal that HIV/AIDS affect women and men but it affects women differently than men.

In the focus group, the participants were asked whether men and women who are living with HIV/AIDS are treated differently. Most participants felt that men were treated with more dignity and respect than women. Even though there were contrasting views from some participants, the personal experiences of the participants who felt more stigmatised because they were women were revealed in their statements.

..... in the family they respect the man more than the woman. If you know, if you are HIV positive and the man is also HIV positive, both partners. If he is working, you also working during the day then they expect us to come and cook at night and also you must also like come and wash the clothes for him and also the children are also depending on you at the same time.

The men are being respected more than women.

4.4.1. Women and HIV Stigma

Being a woman, a component of the lived experience was the reality that stigma and discrimination emerged as being unusually multiple and complex. The participants described how they were doubly stigmatised both as 'women' and as 'people living with HIV/AIDS' once their status was known.

..... and even for women if they are sick and their family didn't know that they are HIV positive, they will say you have HIV. Even if you are just coughing or you got the flu, they will say she is HIV positive. But for a man they will always protect him until they are very sick.

Participants felt that the behaviour of a man, which may have led to him becoming infected with the disease, was simply justifiable while negative social responses from the family were more common for a woman.

...to me if I was a man maybe I would be treated better because we are still living with families who, if a guy is HIV positive and he is sleeping around they will say he is showing his manhood but if you are HIV positive they say you are sleeping around.

These findings reveal that HIV positive women are treated differently from men. Men are likely to be excused for their behaviour that resulted in their infection, while women are not.

...it's easy to judge us like women thinking that you were a slut or that you had more than one partner but they won't think that of the man you know. They go more lighter on the men than on us. It's like for them you asked for it and men just innocently got it.

Cultural differences as a component of one's race emerged as another excuse for a man to engage in relationships with multiple partners. A participant explained how a woman who is living with other family

members would be denied the liberty of having other relationships while a man would not be pressurised.

Like a culture and your relationships but it's not so easy to have relationships in the early state because my mother is looking after me, but the man, like if a man is living at the back he has chances to still have other ladies.

Participants felt that if a woman showed more courage than a man to be tested and subsequently to disclose her status, she was subject to unfair and unjust treatment. In this way women are more vulnerable to be affronted by the effects of stigmatisation and discrimination.

Like most of the time men don't find out. They wait until they are sick and then they start to disclose. And even for a woman if they are sick and their family didn't know that they are HIV positive they will say you have HIV. Even if you are just coughing or you have the flu, they will say she is HIV positive. But for a man they will always protect until they are very sick.

RESEARCHER: Do you think it's different for a man? Would they also swear at them, would they gossip?

Ay. No. Do you know when they find out? When the person is dying. They are so secretive till death. They don't say. Nobody knows they got the virus. Nobody knows except himself. He wont even tell his girlfriend. They don't talk about it.

Participants from both race groups highlighted their understanding of why women faced harsher responses and felt that it was compounded by cultural norms within the different race groups.

In our community which is coloured, when you sit in a group in our group meeting, then I will see there's a man who is one of us, a man who has it. But further you wont see it or men are scared to talk. You wont hear that men have it. We coloureds are very scared to talk. They are very scared to come forward. We coloureds don't want to talk even up to today.

A woman will come out first with it than a man because my boyfriend took long before he could tell me he has it. And he doesn't talk about it. If he's in a group then he will talk about it but nowhere else.

A participant from a Black community reverberated the same response, emphasising the difference for a man and woman living with the disease:

Like I could say in my community, what is happening is that people do not talk to the males but if it's a female people will point fingers at you and say that that's the one who is HIV positive.

4.4.2. The impact of gender culture on HIV/AIDS

There has been increasing awareness that prevailing relationships within and between the sexes, or gender relations as they are usually called, affect not only the development of the epidemic, but the manner in which individuals, groups and communities respond.

Gender does not distribute power equally between men and women. While men are constructed as thinkers, public speakers, decision-makers and property owners, women are constructed primarily as domestic beings, who belong to the home or in the kitchen (Dube, 2003). The implications of this stereotype is described by a participant who shared how a woman living with HIV/AIDS is expected to function in her socially constructed gendered role.

A participant commented about the lack of concern, which was displayed by the family members of her female relative.

My aunt and uncle was treated differently. When my uncle was sick everyone helped but when my aunt was sick they didn't help. When my uncle needed something they give it to him but when my aunt was like that they told her to lift herself up and go and fetch it.

..... all the responsibility is on your shoulders... you may be sick like say you HIV positive and if your child is sick or your husband is sick then you take care of that child or your husband. And they don't see you differently, that they have to help you. They still depend on us to help them because you the woman, you the wife, you the mother.

..... Even though you are positive you must still be a wife, you must still be a mother, you must still work.....

The findings reveal that participants of this study have been brought to realise that gender is a major driving force behind the AIDS epidemic. It has been argued that social constructions of HIV/AIDS draw in gender inequalities to stigmatise individuals, families, children and communities (Karim, 1998; Tallis, 1998). A participant illustrates how gender relations and inequality impacts negatively on their experiences. Men resort to violence and abusive behaviour.

The men abuse the women. If you find out at the clinic there is more women than men. Men don't want to come out then the men are abusing the women at home.

As reflected in the literature, HIV/AIDS related stigma and discrimination therefore plays into, and reinforces existing social stereotypes and inequalities that make women seem inferior to men.

Also the culture respects the man more than the woman because they say like the man is the head of the house. Also if my husband is HIV positive, his mother will treat him like an egg, you know, but we ladies..... but they are respected.

Men are more respected. If the man tested HIV positive, you as the woman, he can force you to come for the test because of that you need to respect him as the head of the house but you as a woman, if you can be tested HIV positive and tell him the news and then tell him, Okay to go to the counsellor and be tested, he can refuse and say I don't want to.

A participant shared how a man, unlike a woman, is fully entitled to have sex with multiple partners. Women who know their status are scared to tell their husbands. Because of their money and the lack of it amongst some students, some men lure poor young girls, infect them and move on.

... for example if the woman has been diagnosed as HIV positive she needs to talk to her husband now to find out where did it come from. She knows that her husband is the only person who she sleeps with. How is she going to approach the husband? How is she going to tell the husband I went to hospital and this is what happened.

The majority of teenagers go out with older men then these men support them with money and stuff like that and most of the parents are not working. They are on school. They need stuff for their school and the parents can't afford to buy them the things that they need so by going out with older men like taxi drivers and by going out with them they give them money and they can buy the things that they need.

4.5. Intervention, Support & Coping Mechanisms

These findings reveal that participants seemed to seek support from various sources. Goffman (1963) alludes to an 'in-group alignment' with like individuals (i.e. other HIV positive women) finding strength in a shared positive identity. Goffman's (1963) assertion parallels the need identified in these participants to find a sense of belonging within a community that does not compel them to recognise their HIV status and its implications. The results, which reveal that not all of the support that was received was positive, are further discussed illustrating how three particular agents of intervention were engaged and the outcome for participants.

4.5.1. Support Groups

The participants indicated that coping with HIV/AIDS, as a woman is a difficult experience. This is because of socio-cultural expectations that include domestic demands on women as well as the stigma and discrimination that is experienced. Most of the participants were members of a support group. Some participants who reported finding the support group a valuable strategy for coping were now supporting others. Participants alluded to the nature of support needed by men as being

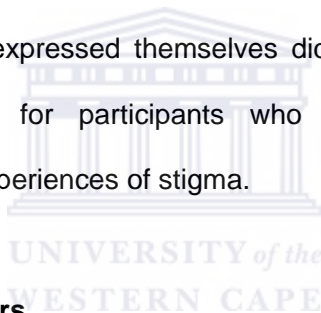
different to that of women if it is to yield positive outcomes. Participants maintained that men in their communities, in particular, are resistant to disclose their status.

.....men do not like talking about their issues compared to women. they hide themselves, do not want to reveal their problems to women so they hold everything inside so they can not be treated the same as women because women can talk to others while men can not talk.

My man does not want to talk to people. They do not disclose when you try and push them they do not want to do it. You just end up fighting because they do not want to disclose.

Sometimes you will find that a man will test and know, but not disclose to a person they are staying with.....

Most of the participants were members of a support group. Those participants spoke with less emotion than participants who were not receiving support. The manner of ease in which participants who were part of a support group expressed themselves did not however conceal the effects of rejection for participants who shared their feelings of discrimination and experiences of stigma.



4.5.2. Health Care Providers

Caregivers such as healthcare providers have a responsibility towards PLWHA to take great care to avoid adding to their burdens and pain. These findings reveal the extent to which women are stigmatised and discriminated by health care systems. Lack of confidentiality and sensitivity has been repeatedly mentioned as a particular problem in health care settings (Shisana, Hall, et al., 2003). This is evidenced in what was referred to by this participant:

The folders in the clinic are marked and whoever is working in that section will know that if there's a M inside your folder that you are HIV positive. Or people will maybe see you like if there's a M next to your folder then they know exactly that you from Room 5.

Many women living with HIV/AIDS do not get to choose how, when and to whom to disclose their HIV/AIDS status as a result of distrust towards this important agent of support. A participant sadly related her experience.

If you came to collect your medication they will shout so that everyone can know you are HIV positive and also there are sisters who, if you ask, where can I go, I'm coming for ARV treatment or I'm HIV positive, which side must I go? They will tell you that why don't you ask someone else. I didn't infect you If you are HIV positive and you are pregnant and you go to them and say "I'm in labour pains and you show them your medication..... they will even shout and say ' you are going to give birth to a HIV baby'..... And say you are sitting there and your neighbour come in and the counsellor came and said, 'how are you feeling today' right in front of your neighbour.

Health care professionals emerged as playing a critical role in the lived experience of social support. The findings reveal a description of unsatisfactory health care resulting in women's severe stigmatisation.

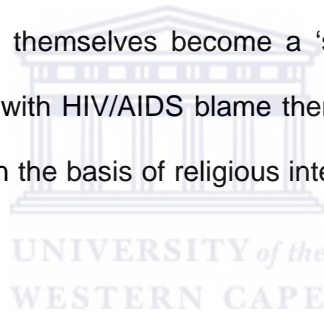
4.5.3. The Religious Community

It is argued that in the spiritually rich environment of Africa, the factor of religion (Du Plessis, 1997) plays a powerful role in cathartic experiences. The meanings around religion and faith, the belief in a higher entity or power and the messages of redemption and liberation, are very effective in terms of tension management in a specific situation of demand. They offer a perspective that allows for real and explicit coping (Du Plessis, 1997).

Socially, HIV/AIDS affects relationships at all levels and the findings highlight its impact on all aspects of life. It impacts individuals, families, communities and nations. Religious or moral beliefs lead some people to believe that having HIV/AIDS is the result of failure that deserves to be punished. The findings reveal that lack of education in the church brought self-judgement to participants as they resolved to see their status as a spiritual matter, which they could not change. This evidently caused an internalisation of pain.

From my side I just feel whatever God gives me I will accept and there's like sometimes when you like sit still and you like think why me, what did I do to deserve this but then again I talk to myself. I can't blame anyone, I must blame myself.

It has been argued (Gyssler, et al., 2000:1) that there are instances where people's beliefs may themselves become a 'source of great pain'. This occurs when people with HIV/AIDS blame themselves and feel as if they deserve the illness on the basis of religious interpretations (Gyssler, et al., 2000).



So I said like for me its just whatever God gives I must accept and that day, from that day onwards I just told myself even if I must get a cripple child or whatever, that is just gonna be mine. That's what God gave me to accept.

A participant who found the courage to disclose her status to her mother was faced with her mother's denial as she felt that God had not told her.

.....my mommy. How was she? How was she reacting? Strangely she was when I was telling her she was telling me that because she's a born Christian. God didn't show her any.... There's no signs or symptoms or something that showed her that what I'm talking is the truth so she won't believe me and just it's something that I made it up.....

A participant, in response to a question raised about how her status has brought about changes in her life shared how her faith in God helped her. Her response reveals that the church and other religious communities have a challenge in confronting and reducing stigma for women living with the disease. Furthermore, it is revealed that the religious community is often referred to as a source of support.

....what changed is that I met God... I have changed all things I used to do, I do not so I am with God all the way

Since the outbreak of HIV/AIDS, there are more sick people who need to be visited and encouraged. There are an increasing number of orphans who cannot be absorbed by their overburdened extended families and who need to be comforted and cared for. There are more desperate widows who are grieved and who may be impoverished by the sickness of their former husbands or dispossessed by relatives, and who need counselling, care and support. There are more grandparents grieved by the death of their children and burdened by care for their orphaned grandchildren. There are many who are dying and need to be prepared to die peacefully and with dignity (Dube, 2003).

The findings reveal that many women who are confronted with stigma, who felt lost in hopelessness, despair and fear, in their quest for support and hope and to cope better, turn to the church. This participant sadly revealed how the church failed in accepting her because of her status and added to her pain of stigmatisation.

It's a thing like.... They don't take us as if you are human beings so they don't accept because in our community still there is discrimination. If you come and disclose to your community and in the church. the Pastor they don't know about HIV they take it like HIV is a sin

This participant suggested to the rest of the group after their expressions of concern about how their children were stigmatised or how they were stigmatising others. She felt that, amongst other systems of support, the church had a role to play in educating children who were contributing to the pain of PLWHA because of their negative behaviours.

Another thing at church, in places and clinic and other places they should talk to people who are negative to talk to their children to stop laughing and making fun of people who are positive.

It is widely argued that family members, representatives of religious communities, health-care providers and counsellors are important sources of psychological and spiritual support for people living with HIV/AIDS (Parry, 1990; Barnett et al., 1992; Rugamela, 1999; UNAIDS, 2000a: 93).

Religious groups, in general, have a reputation for responding to the issue of HIV/AIDS in negative terms. Factors that influence this perception have included judgmental comment from religious leaders, debate about condoms, commercial sex and harm reduction approaches (International Conference on AIDS & Religion, 1997). Sontag (1989:54) asserts that 'plagues are invariably regarded as judgements on society'. As a result, people with HIV have experienced rejection by religious people, congregations or institutions.

These findings reveal that stigma is perceived as highly insidious. There is a demonstration of stigma everywhere, in the home, in the hospital, and even in the church. This demonstration has been confirmed by the related experiences of neglect and rejection, particularly within households and health settings.

Common forms of stigma were gossip, verbal abuse and accusations, to which women were more vulnerable. Another form of stigma that emerged from these findings was the distance with which people positioned themselves and the person living with HIV/AIDS. Despite the widespread knowledge and awareness of how HIV is transmitted, there were still reported fears about contagion through casual contact. Blame for infection was placed on women. Very little sympathy or respect was expressed to women who were living with HIV. Instead they were open to blame, ridicule and rejection.

These findings reveal that the spread of HIV/AIDS within families highlights a concern. In the family, stigma was manifested in the forms of verbal abuse, rejection, eviction and restrictions on the person. This behaviour was reported to be more intense for a woman than for a man.

In the health care setting, the most extreme forms of stigmatisation towards people with HIV/AIDS were found in the lack of confidentiality. Participants reported that they were clearly made to feel different from other patients in many instances.

In summary, the analysis of the focus groups provided in-depth descriptions of the lived experiences of women living with HIV/AIDS. HIV/AIDS appeared to have a strong impact on their self-perception, emotional stability and the construction of individual and family identities. Findings, recommendations for future study and limitations to the study will be discussed further in the Chapter 5, which concludes the study.



CHAPTER FIVE

CONCLUSION AND RECOMMENDATIONS

5.1. Introduction

This study focused on a group of 36 women living with HIV/AIDS within two contemporary South African communities. This final chapter highlights the major issues that emerged from the findings derived from the lived experiences of stigma for the participants. In this chapter a summary of the study will be provided and specific attention is given to the implications of the study. Furthermore in this chapter recommendations and limitations of the present study will be indicated.

5.2. Findings

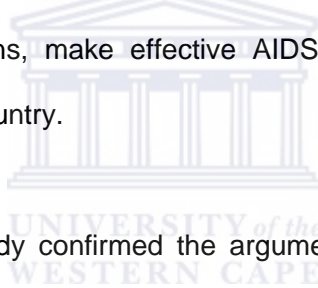
Results of the study confirm the findings of Leenerts & Magilvy (2000) that individuals, when diagnosed with HIV protect themselves through a process of either hiding their status or selectively disclosing their status. In this present study selective disclosure was chosen and in most cases participants confided in their mothers.

The participants' construction of an HIV-diagnosis was that of being a devastating life-altering event and a 'death sentence'. The participants also felt ashamed of their positive status and in some cases they withdrew from those people who were important in their lives prior to the diagnosis. This caused them extreme loneliness and isolation. Given a discourse with which HIV/AIDS was

constructed as a fatal illness and an illness which caused blame, the participants responded mainly by keeping their status a secret. With an awareness of imminent death, participants who were mothers living with HIV, described their fears and concerns as they worried about who would take care of their children. These fears and concerns were further compounded by the broader response to their children who reportedly are stigmatised through association with their mother. Stein (2004) suggests that parental disclosure is important for both the child and the parent. It is argued that mothers tend to be distressed about their children who are most vulnerable under the circumstances. Barnett et al. (1992) and Rugamela (1999) confirm that life can be difficult for children affected by HIV/AIDS. Implications of this study must address strategies to assist mothers to recognise the importance of disclosure to their children as well as to enable mothers to prepare adequately for the future by educating them how to relate to their children in terms of their fears and concerns.

The results indicate that women receive less support and are more stigmatised because of the impact of distorted and unequal gender relations in society. In the lives of participants, gendered power relations related to their experience of interpersonal abuse as well as victimisation within their families and communities, which had a detrimental effect on their well being. The literature reviewed suggests that in most societies, dominant gender constructions and ideologies determine how and what men and women know about sexual matters and sexual behaviour. This study confirms that of UNAIDS (1999) that women are often poorly informed about reproduction and sex, while the expectation is

often that men know much more and are more sexually experienced. This study has highlighted a number of growing gender-related concerns that have important consequences for HIV prevention, including rape and violence against women and the lack of support for women. The study therefore further reinforces the argument that it is imperative to challenge the spread of HIV from a gender perspective, which must address the inequality of gendered power relations, in research, prevention and supportive programmes for women and men. There has up until recently been a marked lack of attention to the ways in which power, roles and dominant social expectations facilitate vulnerability particularly for young, disempowered men and women. Strebel (1993) argued that we are confronted by a complex web of contradictory representations in which the specific historical contexts of the AIDS epidemic in South Africa and discourses of gendered power relations, make effective AIDS treatment and prevention difficult for women in this country.



The participants in this study confirmed the argument that there is no shared responsibility created or encouraged in public messages about HIV/AIDS but that women are by nature made accountable for the disease (Richardson, 1989; Burry et al., 1992). Men are likely to be 'excused' for their behaviour that resulted in them living with the disease, whereas women are not. What emerges from the literature is that the role of men needs to be addressed, particularly attitudes and behaviour that are sexually irresponsible and that result in a certain death sentence not only for themselves, but for millions of women and children. Given the powerful role of men in society, the study further reinforces the need to

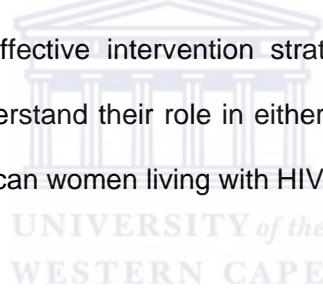
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address HIV/AIDS interventions and strategies targeting men in an attempt to impact the vulnerability of women to HIV.

The literature reviewed indicates that discrimination and stigma has not ended and this is clearly illustrated in the study. Women continue to be seen as vectors of HIV and remain the primary agents of blame and stigma. Despite the devastation AIDS has wrought on women, there is no quilt for them. Women in South Africa do not appear to have the camaraderie or the loving network that has been created for example, for gay men (Bunting, 1996).

The results of the study further indicate that due to stigma attached to women who are living with HIV/AIDS, they have encountered rejection or abandonment in their communities, from their families, partners and even health-care providers. The results reveal that a lack of knowledge of HIV/AIDS in the community, families and agents of support, is a contributing factor to the stigma experienced by women who are living with HIV/AIDS. In the health care setting participants experienced unsatisfying interpersonal relationships with and responses from health care providers. In the lived experiences of these participants they demonstrated exposure to stigma. Health care providers lacked the ability to provide support, tangible assistance and informational provision. This study is a reflection of how HIV/AIDS is fuelled by myths and misconceptions around transmission and social constructions of gender and HIV/AIDS, which reinforce stigmatisation, and 'othering' of especially women.

The experiences documented here show that women and girls are the ones bearing the burden of the disease of HIV/AIDS. Stigma prevents many women from finding out their status and HIV positive women who publicly acknowledge their status face discrimination and violence. Studies focussing on low-income and minority women who are living with HIV/AIDS reported significantly high levels of depressive symptoms than men. According to Catz et al. (2002) and Murphy et al. (2002), the differences in distress levels between women and men are ascribed to discrepancies in contextual issues such as poverty, childcare responsibilities and the stigma and social isolation that women living with HIV experience. The findings of this study show a correlation with findings from other studies of this kind. The importance of addressing stigma, particularly the gendered dimensions, and further community education regarding HIV are evident from this study. Effective intervention strategies must seek ways to enable communities to understand their role in either undermining or supporting the lives of Black South African women living with HIV.



The results further confirm the literature reviewed with respect to the argument that support systems are key to women coping with their infection at a personal, social and community level (Strebel, 1993; Richardson, 1989; CAA, 2000; Burry et al., 1992). While familial support does not always appear to be available for most women, they do appear to receive some positive support at an organisational level in a structured support group setting. Most of the participants were members of a support group. Those participants spoke with less emotion and more confidence than those who were not receiving support and clearly

valued the support group. The manner of ease with which participants who were part of a support group expressed themselves, did not however conceal the effects of stigmatisation on these participants.

Van Dyck (2001) suggests that in support groups members of the group become experts of their own lives and are empowered to help care and satisfy the needs and concerns of other groups members. The results of this study verify Van Dyck's (2001) assertion. Other studies have confirmed that counselling services and support structures prove to be a major support for participants, who share similar experiences and are able to learn more about HIV/AIDS (Dorn et al., 1994; Were, 2000; Richardson, 1989).

The findings have revealed that women living with HIV/AIDS rely greatly on religion as a coping strategy and support mechanism. Results demonstrated that belief in a God who was seen to be in control was a critical aspect of the lived experience of social support. Fryback and Reinert (1999:13) postulate that 'spirituality is viewed often as a bridge between hopelessness and a sense of meaning'. Spirituality can provide individuals with a basis for coping by giving them a sense of purpose and meaning. Participants described the church as a significant aspect of support, and interpersonal relationships within the church were particularly crucial for participants. In this respect however, participants described experiences of stigmatisation within the church and its community. Participants articulated the lack of knowledge and understanding of HIV that exists in the church and as a result, they felt that the church community was no

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different from any other community. They were constantly reminded that they were different and they felt unloved and rejected because they were living with HIV/AIDS. Stigma and discrimination remain perpetuated in the church as HIV is seen as a form of God's punishment. This is fuelled by some biblical interpretations, which link HIV/AIDS as sin or being dirty (Dube, 2003). The implications of this study must address an alternative approach of doing theology in the context of HIV/AIDS. Such an approach will assist in developing a theology, which affirms the sanctity of life.

5.3. Limitations of the Study

The present study attempted to explore and deepen awareness of the lived experiences of stigma for thirty six women living with HIV from two local communities in the Western Cape, South Africa. The results emerged as rich descriptions and provide deepened understandings of the experiences of the participants within their specific socio-cultural contexts.

The small homogenous sample group however compromises the generalisability of the study. The data extrapolated from their reports reflect their particular experiences as black and coloured women living in the two specified Cape Town communities. This study therefore has limitations, as the results are bound within a specific context and to a specific group of women. For example, since the majority of women are unemployed, with those who are employed having completed only their basic education, their experiences would be different to those who have completed either secondary or tertiary education or who have a

different socio-economic status. The purpose of the study was not to draw conclusions representative of all women living with HIV/AIDS in these communities. This study aimed to give meaning to the multiplicity of situations women face when living with HIV/AIDS, and the issues they are confronted with, particularly focusing on the experiences of stigma. Future research could be extended to other groups of women within the broader South African context.

This study is further limited by cultural context and would have provided a richer interpretation if the researcher was able to understand Xhosa. In Chapter 3 on research methodology it was explained that 3 of the 6 focus groups were conducted in Xhosa.

While the limitations of generalisability is important to note, of equal importance is the assertion by Chomsky (1989:11,12) that 'what is at issue is not the honesty of the opinions expressed or the integrity of those who seek the facts but rather the choice of topics and highlighting of issues, the range of opinion permitted expression, the unquestioned premises that guide reporting and commentary, and the general framework imposed for the presentation of a certain view of the world'.

5.4. Recommendations

As highlighted in the literature this present study confirms many of the findings made in other studies e.g. (Seidel, 1998; Strebel, 1993; Tallis, 1998; Harrison, Smit & Myer, 2000; Take Control, 2001) that have examined behaviour and women's experiences in the HIV/AIDS context. In the following

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recommendations, reference is made to the findings in relation to: gender, stigma and responses, HIV/AIDS knowledge and awareness, intervention and further recommended research.

This study has highlighted the biological and social reasons for the demonstration that women have higher HIV prevalence than men. Women's health involves their emotional, social and physical well-being. The consequences of HIV/AIDS reach beyond women's health. In an attempt to ensure that more women live positively, both emotionally and physically with HIV/AIDS, and do not die without disclosing their status to those closest to them, it is suggested that women be empowered continuously, guaranteeing them their economic, human and social rights (Gupta, 2001). The author asserts that in the AIDS epidemic, these rights will not only prevent death but will also empower those living with HIV/AIDS. HIV/AIDS demonstrates how the socio-cultural climate in South Africa and Africa in regard to gender inequality is not simply a matter of fairness and justice. Gender inequality may be fatal (Urdang, 2001). Interpretations and meanings influence all our communities, which means the definition of a 'good' South African woman will need to be redefined (Esu-Williams, 2000). African men need to be engaged in changing this definition if progress in the fight against HIV/AIDS is to evidence success. The position of women in families and communities and their power in relation with men must be strengthened. It is recommended that consideration of gender issues, gender-related vulnerability to HIV/infection, gendered stigma, gender imbalances and inequalities that exist for women who are living with HIV, be integrated into HIV

programmes. Socially constructed ideas of what constitutes a 'bad' or 'good' woman remains to be challenged in society in an attempt to change the perceptions of how men and boys view girls and women. Such changes will impact not only on the spread of HIV/AIDS but also on the quality of life of those already infected.

This present study highlighted the numerous ways that women who are living with HIV/AIDS are stigmatised. Women have been stigmatised for their HIV status, for their gender, their sexuality, their poverty and their minority status. The results of this present study illustrated how disclosure led to rejection and stigmatisation within the family, the community and health care settings. It is recommended that the making and implementation of policies and laws to insulate people living with HIV/AIDS from discrimination and stigmatisation should be implemented in all organisations, NGOs, community and faith-based organisations. Staff members should be adequately trained to identify and deal with stigma, critically examining their own attitudes and perceptions and methods of communication. In the face of the grave threat posed by HIV/AIDS, all role players need to rise above their differences and combine their efforts to support those living with HIV and to prevent further infection. They should be encouraged to openly challenge the 'double' stigmatisation that poor women of colour face in relation to HIV/AIDS. Of utmost importance is the dramatic scaling up of local and national programmes to counter stigma and discrimination and related forms of intolerance in the context of HIV/AIDS in an attempt to challenge broader inequalities, power relations, women's role and the gendered nature of stigma.

This present study highlighted the lack of knowledge about HIV/AIDS and demonstrated negative attitudes towards people living with HIV/AIDS. Participants of this study demonstrated how upon receiving their HIV positive diagnosis, they knew very little about HIV and as result believed that their death was imminent. It is recommended that intensive education programmes, which adopt a systematic and co-ordinated approach, should address knowledge areas of HIV/AIDS prevention, rights, treatment and care. Awareness campaigns need to present messages that expose the issues and needs of people living with HIV/AIDS.

The lived experience of HIV highlights the centrality of a network of relationships considered constituent aspects of social support. This network of relationships includes interactions with health care providers, religious community and in support groups. It must be highlighted that Interpersonal relationships within this network either satisfy or do not satisfy specific needs and can actively support or actively undermine the quality of life of those living with HIV. Within this network, examinations of the content of various interpersonal relationships provide evidence that a polarity exists within the lived experience of social support. The support groups, health care providers and the religious community emerged as a constituent aspect of the lived experience of social support, however, within the notion of each of these constituents, an experience defined by either acceptance or rejection, could result from HIV disclosure. The data provided an understanding that interpersonal relationships, which were experienced as

satisfactory, were defined by instrumental support, tangible assistance and emotional connectedness. Unsatisfactory interpersonal relationships, on the other hand, lacked these important elements.

It is therefore recommended that health staff receive adequate training on essential aspects relating to health care and HIV/AIDS. In the face of the challenges confronting the church and its leaders, it is recommended that user-friendly handbooks be compiled and made available within faith based organisations. Educational resources should serve as an aid to break the silence and stigma, calling role players to HIV/AIDS prevention, provision of quality care and mitigation of the impact. It is recommended that support structures for women living with HIV/AIDS offering services like counselling and support groups as well as addressing methods of coping with stigma, facilitating an enabling environment for women living with HIV/AIDS, should be encouraged and facilitated. Women should be motivated to talk and discuss their status openly in an attempt to de-stigmatise the disease and provide support and care for those living with HIV/AIDS.

Further research should be done with women living with HIV/AIDS from different cultures, focusing on how women make sense of their world and illness experiences within their specific social and cultural contexts. There appears to be a gap in the literature where other minority groups in South Africa, such as low-income white women who are living with HIV, are overlooked in research agendas and also need to be studied. Extensive research studies need to be

conducted on South African men who are living with HIV/AIDS, given the dominant discourse of gender inequality. A study of this nature would identify the differences in the lived experiences for men in comparison to women. Further research should be conducted on families with members who are living with HIV, the effects of the illness on their relationships as well as planning for future needs. Further research needs to address action against HIV-related stigma through a deeper understanding of its impact. The development of new and stronger forms of data collection and analysis should be employed to illuminate the relationship between poverty, gender, sexuality and race, as determinants of HIV/AIDS-related vulnerabilities should be further researched.

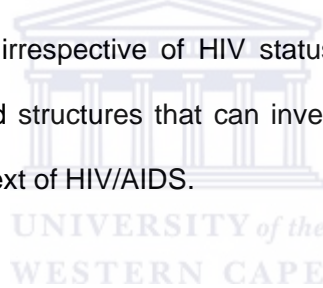
5.5. Conclusion

The present study aimed to explore and describe the lived experiences of stigma for women living with HIV/AIDS from two Cape Town communities. The study highlighted the vulnerabilities of particularly poor black and coloured South African women, exploring various realities contributing to the stigmatisation of women in these communities.

The research findings had implications for changes in the provision of services by health care providers, educators and agents of support who currently play a role in provision of care and intervention. It is particularly imperative to implement measures to increase the capacities of women to protect themselves from the risk of HIV infection, principally through healthcare services, and through prevention education that promotes gender equality within a culturally gender-

sensitive framework. However, once infected, the need for impacting on current social and community responses to those living with HIV/AIDS, in order to facilitate quality of life for those infected and affected, is a priority area for intervention.

HIV/AIDS stigma is not only a problem of ignorance but also of social prejudice and therefore research on the problem should address and contribute to social transformation. It is at community and national level that HIV/AIDS related stigma and discrimination is most effectively combated. Monitoring and fostering of the responsibility of all citizens in the area of human rights within the context of HIV/AIDS, in particular in addressing stigma and discrimination, will depend on the extent to which communities and community leaders advocate for inclusiveness and equality irrespective of HIV status. This will depend on the existence of institutions and structures that can investigate violations of human rights that occur in the context of HIV/AIDS.



Importantly, gender inequalities and stigma have not only permeated dominant images and cultural constructions of the epidemic, they have also been reproduced within it. Women with HIV/AIDS have frequently been blamed for their condition, being seen not only as individuals living in contexts of marginalisation and inequality, but also as the causes of their own misfortune (Henderson, 1996). This kind of experience emerged clearly in this study, and underpins general indifference to the plight of women who are living with HIV/AIDS. While feminism may have been discussed in the West for several

decades, in many parts of the world its impact has not been felt at all. There still exist major inequalities between women and men in all aspects of living. HIV/AIDS, both in terms of prevention and mitigation of impact is no exception. Many countries still have patriarchal rules governing women's place in sexual relationships. In situations where power is afforded to men only, a woman is unlikely to be able to take the necessary measures to protect herself from HIV/AIDS and subsequently to resist bearing the stigma, which has become the weight of silence.

Challenging stigma and related forms of intolerance in the context of HIV/AIDS requires commitment at all levels including by governments, civil society, communities and individuals. The context for such action is the paradigm shift that has occurred in understanding and responding to the epidemic. HIV/AIDS is much more than a health problem. It touches human conditions, human security, human rights and social and economic development. A human rights framework is essential to encourage a reduction in HIV/AIDS-related stigma and discrimination. The spread and impact of HIV is fuelled when human rights are violated, respect and fulfilment of human rights is vital to lessening the adverse impact of the disease.

Supportive interventions and an effort by all role-players could make a difference in allowing women to construct more positive identities as those living with a chronic illness. While more positive, empowering social discourses around HIV/AIDS do exist, it is the negative, more destructive social discourses that

individuals draw on when first diagnosed. It has been argued that HIV/AIDS has emerged as a disease with the greatest capacity to stigmatise (Sontag, 1991). This has been painfully brought to reality by the shared experiences of the women who have been studied in this project.



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APPENDIX A – Focus Group Questions

- 1) What are your views about HIV/AIDS?
 - a. What do you think influenced you to hold these views?
 - b. Do others share your views in the family and community?
 - c. What are some positive things in your community that are supporting of people who are living with HIV/AIDS?
 - d. What are some negative things in your community that are against people who are living with HIV/AIDS?

- 2) How would you say people living with HIV/AIDS are treated in the family?
 - a. Are you as a woman living with HIV/AIDS treated differently?
 - b. How about males living with HIV/AIDS? Are they different (treated differently)?
 - c. Please share an example of how they may be supportive or not supportive?
 - d. What are your views about the role of the health care on this matter?

- 3) How long did it take before you disclosed your status?
 - a. Who was the first person you spoke to?
 - b. Why did you choose this person?
 - c. How did this person react?

- 4) How did your husband or partner and other members of your family react? How did the community react?
 - a. Is there a difference in the way the community deals with people who are HIV positive?
 - b. Are there any restrictions placed on you because of your status? Where?
 - c. Do you think it is different for a man? How?

- 5) How has your life changed after being informed of your status?
 - a. At home, in the family, within the community
 - b. Do you think it is different for a man?
 - c. Have you had any counselling? With whom and how were you able to access counselling?
 - d. How about a support group?

- 6) Is there anything else you might want to add regarding HIV and AIDS?

APPENDIX B – Informed Consent Form

**INFORMED CONSENT FOR PARTICIPATION
IN MASTERS STUDY UNIVERSITY OF THE WESTERN CAPE, BELLVILLE**

I, Gail Roman, am a Masters Student in Women’s & Gender Studies at the University of the Western Cape, Bellville. I am undertaking a study of the stigma and deprivation suffered by women living with HIV/AIDS. This study is being supervised by Prof. T. Shefer, Director: Women’s & Gender Studies.

As a participant in this study:

- You will be joined with other participants and asked to participate in a group discussion and respond to questions that I will ask.
- You will be expected to attend only one session.
- The discussion will be taped and the tapes will be kept in safe custody at my home. My supervisor may request to listen to the tapes. In this case it will only be my supervisor and I who would have access to them.
- You may withdraw from the group or choose not to respond if you feel uncomfortable during any part of the discussion.
- The benefits to you may be that you could experience a healing process as you hear others share firsthand the experiences of someone who is living with HIV/AIDS.
- The risks to you may be that some of the questions may make you feel uncomfortable. You may meet someone at the venue whom you may not have wanted to disclose your situation with.
- This research will be used as part of a larger study, which is being conducted by the Human Science Research Council.
- Your confidentiality will be protected. I will not use your name in the study in order to protect you. I will not discuss your circumstances or situation with anyone.

Please feel free to contact me at Tel: 959-2234 or Prof. T. Shefer at the same number, should you require further information or need a referral for counselling due to your participation in this study.

I _____ understand and agree to voluntarily
NAME OF PARTICIPANT

participate in this study to be held on _____ at
DATE OF INTERVIEW

PLACE

Signature: _____ Date: _____

PERSONAL INFORMATION

CONFIDENTIAL

1. NAME & SURNAME OF PARTICIPANT: _____

2. AGE GROUP: (Please tick appropriate block):

18-25

26-35

36-45

over 46

3. HIGHEST STANDARD COMPLETED AT SCHOOL: _____

4. PLEASE TICK ONE OF THE FOLLOWING:
MONTHLY INCOME AT PRESENT:

Unemployed: _____

R2 000 & Below: _____

R4 000 & Below: _____

Above R4 000: _____

5. FOCUS GROUP NO: _____

6. VENUE: _____