

WOMEN'S EXPERIENCE OF BEING HIV POSITIVE,
THE STIGMA RELATED TO HIV AND DISCLOSURE
OF THEIR STATUS

By

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This dissertation is dedicated to:

My mother dearest

Nomathemba Dlamini

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SUMMARY

This project is part of a larger study of the Serithi project in which semi-structured interviews were conducted with three hundred and seventeen HIV positive women from disadvantaged locations of Tshwane. In this study, the focus is on women's experiences of an HIV positive diagnosis and the stigma associated with HIV and their level of disclosure. An analysis was made to whom they disclose, why they choose to disclose and the reaction of the people disclosed to, as well as reasons some people decided not to disclose.

Theoretically, the Social Psychology approach was used to provide a theoretical framework as it attempts to understand the relationship between individuals, groups, and behaviour, invariably understanding the relationship between HIV related stigma experienced and the levels of disclosure of the women. As the aim of this study is to gain a deeper understanding of the experiences of HIV related stigma and disclosure encountered by South African HIV positive women, a combination of qualitative and quantitative measures was used.

It was established from the research results that upon diagnosis, most women experience negative emotions and thoughts including shock, fear of death, sadness, anger, self-blame and denial. These reactions, however, over time seem to fluctuate and positive reactions such as acceptance of the HIV positive diagnosis and positive thinking come to the fore.

Of the three hundred and seventeen respondents used in this study, only one hundred and ninety three women (61%) disclosed their HIV status to at least one person, being either partners (44%), family members (16%), parents (12%), friends (11%), in-laws (1,5%), and or people at work of which less than one percent of the women disclosed to, while 124 (39%) of the women did not

disclose to anyone with the exception of the research assistants involved in this study.

The issue of disclosure was analysed, and the most people disclosed to were partners, family members and parents. The women stated that it was easy for them to disclose to these people because they knew that they would not be judged and ridiculed. Instead, they felt assured that they would receive unconditional acceptance and support upon disclosure. Reasons for not disclosing included the fear of discrimination, rejection and blame, lack of trust and a supportive relationship.

HIV related stigma was assessed through three different types of stigma, namely;

- 1) Experienced personal stigma (expectations of stigmatised individuals of how others will react to their condition),
- 2) Perceived community stigma (how the respondents think most people in the community feel and react towards HIV) and
- 3) Enacted stigma (the actual experiences of discriminatory acts due to their HIV positive status). From these assessments, it was established that respondents perceive community stigma to be the most prevalent and more negative than felt or personal stigma and enacted stigma, which was the least negative.

Correlations between the various measures of stigma and disclosure showed that the women's decision to disclose their HIV status is not only related to their stigma scores. Levels of personal stigma only played a role in disclosure to family members and friends and not in disclosure to partners. Perceived community stigma, which was high, did not have an impact on the level of disclosure. Therefore, the decision to disclose one's HIV status is not totally influenced or dependent on HIV related stigma because other variables such as the quality of relationships also play a role. This raises the opportunity for further research as to what other aspects may have an impact on the issue of disclosure of one's HIV positive status.

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CHAPTER 1

INTRODUCTION

1.1 Introduction

This study is aimed specifically at South African women's experiences of being diagnosed HIV positive, HIV-related stigma and how it relates to their decisions about the disclosure of their status.

South Africa is facing a catastrophic AIDS epidemic, with 11 to 20 % of all South African adults infected with HIV, 600 000 children already orphaned by AIDS and as many as 1,600 new HIV infections each day (Shisana & Simbayi, 2002). Today, HIV/AIDS threatens the welfare and well being of people throughout the world. In 2004, an estimated 40 million people were living with HIV or AIDS and 3 million people died of HIV/AIDS related illnesses (UNAIDS, 2004).

Worldwide, HIV/AIDS has created an enormous challenge to public health in terms of methods of prevention, transmission, management, stigma and disclosure. Although first considered a disease of gay men or drug addicts, HIV is escalating among the heterosexual population. Women compose almost half (45%) of new HIV infected adults worldwide (UNAIDS, 2004) and an estimated 19.2 million women are infected.

The impact of HIV/AIDS on women is particularly acute. In many developing countries, South Africa being the focus, women are often economically, culturally and socially disadvantaged and lack equal access to treatment, financial support and education (Strebel, 1993). In most societies, women are mistakenly perceived as the main transmitters of sexually transmitted infections (STI's). Rejection also occurs in gender terms, with men often blaming women for infecting them with the possibility of the man physically abusing or even leaving her for disclosing her status (Strebel, 1993).

The devaluation of identity and discrimination associated with HIV-related stigma do not occur naturally. Rather, individuals and communities generate the stigma as a response to their own fears. HIV-infected individuals, their loved ones, and even their caregivers are often subjected to rejection by their social circles and communities when they need support the most. They may be forced out of their homes, lose their jobs, or be subjected to violent assault. For those reasons, HIV-related stigma must be recognized and addressed as a life-altering issue (World Health Organization {WHO}, 2002).

Finding out about the HIV diagnosis can propose numerous traumatic reactions including: fear of death, deterioration of interpersonal relations, negative emotions, rejection of the HIV antibody test, stress related to the hiding of the condition, anxiety, depression, guilt, loss of support, isolation, difficulties with family dynamics, emotional or physical violence, as well as deterioration of relations with health care providers. After a person tests HIV positive, he or she faces many difficult issues, including whether to disclose their HIV positive status to partners, friends, family, and health care providers as well as how to enter and adhere to care (Herek, 1999).

In all relationships discrimination counteracts trust. This often leaves those infected alone and distanced from the rest of their communities, colleagues, and even family. The fear of discrimination has been shown to create problems for disclosure, since disclosure can contribute to reactions of rejection, leaving the person living with HIV isolated and destitute (Skinner & Mfecane, 2004).

Even though there is now more anti-retroviral medication available, living with the knowledge of a serious and potentially life-threatening infection, is likely to be stressful and difficult. Someone with HIV may remain in good physical health for several years but misunderstanding and fear about HIV and AIDS is still widespread in society, resulting in social and emotional problems for the infected person (Jones, Farina & Hastorf, 1994).

Many people with HIV have seen friends and partners become ill and die a painful death, therefore they choose to tell no one about their diagnosis except for a few trusted friends. This burden of secrecy can be very hard to bear. Living with the knowledge that you could pass a serious infection to someone else can also be very complicated (Herek, 1999).

Around the world, reactions to the AIDS epidemic have ranged from silence to denial to hostility and outright violence. Fear of being branded or socially outcast may prevent most women from being tested for the virus, or even worse, disclosing their status, thus preventing them from protecting their partners and seeking treatment. Women who have or thought to have the virus may be shunned, abused, denied jobs and housing or refused care and treatment at health care facilities. These reactions hamper prevention and treatment efforts and deepen the epidemic's impact (Collymore, 2002).

1.2 Problem Statement

The experience of HIV related stigma by South African women who recently have been diagnosed HIV positive may have an impact on their decision to disclose. Therefore, this research, investigates specifically to what extent do the different levels of stigma i.e. experienced personal, perceived community and enacted stigma, contribute to women's decision of disclosing or not. The reasons for disclosing or not are investigated as well as to whom they disclose and what reaction they experienced after disclosing their positive status.

1.3 Motivation of the Study

The South African Government and several Non- Governmental Organizations have been exploring ways of combating stigma by circulating information, providing voluntary counselling and testing centres (VCT'S), promoting greater involvement of people living with HIV/AIDS in programmes and teaching coping skills. Strategies have also included monitoring human rights violations and

enabling people to challenge discrimination. However, a review conducted by the Population Council in 2001 found that researchers are still faced with major questions of how best to counter the deeply embedded social attitudes and harmful actions surrounding the epidemic (Southern Africa AIDS Information Dissemination Service {SAFAIDS}, 2003). It has been found that relatively few attempts towards countering HIV/AIDS related stigma have been rigorously evaluated, documented, and published around the world. Programmes to combat stigma have not always been tailored to specific cultural settings or populations, which subsequently explains the unexpected failure rate of combating HIV related stigma (Collymore, 2002).

Skinner and Mfecane (2004) state that there still exists a clear need to establish a research agenda for stigma related to HIV in South Africa. Also, stigma is a social phenomenon that needs to be understood at both social and individual level.

Disclosure is an important public health goal for a number of different reasons. First, disclosure may motivate partners to seek testing, change behaviour and ultimately decrease transmission of HIV. In addition, disclosure has a number of potential benefits for the individual including increased opportunities for social support, improved access to necessary medical care including antiretroviral treatment, increased opportunities to discuss and implement HIV risk reduction with partners, and increased opportunities to plan for the future (WHO, 2002).

Along with these benefits, the disclosure of HIV status to sexual partners has a number of potential risks for the individual including loss of economic support, blame, abandonment, possible physical and emotional abuse, discrimination, and disruption of family relationships (WHO, 2002). Therefore, this study would be beneficial in terms of providing a wider spectrum of explanations of the true experience of the HIV-diagnosis and the role that HIV-related stigma plays in the experience of HIV and the levels of disclosure. This study will also explore

factors contributing to disclosure and non-disclosure by South African HIV positive women.

Stigmatising beliefs about HIV/AIDS and associated fears of discrimination often influence decisions to seek HIV testing and disclosure of their status (Schmidt & Goggin, 2002). Among HIV positive women in Sub Saharan Africa, a primary reason for not disclosing their status and failure to seek assistance is fear of stigma (UNAIDS, 2002). According to Parker and Aggleton (2003) stigma is linked to discrimination and therefore poses a realistic barrier to engaging in HIV testing, prevention and disclosure. This study highlights in particular the profoundly stigmatising nature of HIV for these women.

It is only in the 1990's that the world started to recognize the special threat that HIV/AIDS poses to women, yet the stigma it entails and the consequences of disclosure has only recently attracted appropriate attention (Heagarty & Abrams, 1992). Understanding the lived experiences of having HIV and experiencing the stigma and disclosure among South African women with HIV is crucial for the planning and implementation of appropriate health and social care. However, there are only a few South African studies that explore the actual experiences of people living with HIV/AIDS (Sobo, 1995).

If women are to be encouraged to come forward earlier for testing leading to disclosure without being stigmatised, the cultural significance of HIV in African settings needs to be more clearly understood (Anderson & Doyal, 2004). Once a diagnosis has been made, the most appropriate treatment will not be available to individual women as long as the issue of stigma is not properly addressed (Anderson & Doyal, 2004).

1.4 Overview of the Study

This study consists of five chapters. **CHAPTER 2** reviews on the literature written specifically on HIV/AIDS, women and HIV, HIV related stigma as well as

disclosure. It also provides an overview of certain concepts from a social psychology perspective. **CHAPTER 3** provides a detailed description of the method used in this study. In this specific research, a combination of qualitative and quantitative research was used, thus a rationale is provided for such incorporation. In order to provide a clear idea of how the research results were obtained and analysed, sampling, data collection instruments as well as data analysis will be discussed in this chapter. In addition, the ethical procedures will be discussed. **CHAPTER 4** consists of the presentation of the research results, as well as a brief discussion of the correlations that emerged from the variables involved. A discussion of the results and an interpretation in terms of theory will be presented in **CHAPTER 5**. Also, a summary of the entire study with critical evaluation and recommendations for further research will be presented in this chapter.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

In this chapter, literature based on the main concepts that form the basis of this study will be reviewed. Included is HIV/AIDS, HIV related stigma, women and HIV/AIDS, disclosure of HIV status and finally a brief discussion of the theoretical approach used which is namely, social psychology.

2.2 HIV/AIDS

South Africa has a serious HIV/AIDS (Human Immuno-deficiency Virus/ Acquired Immuno-deficiency Syndrome) epidemic, with millions of its people living with the disease. For the country to respond effectively to prevent new infections and provide care and treatment to those who are already living with HIV/AIDS, it is vital to have accurate data and a comprehensive understanding of the epidemic (Shisana & Simbayi, 2002).

AIDS is a condition caused by a virus known as Human immunodeficiency virus (HIV), which impairs the immune system (Larson, 1990). HIV is a virus belonging to the family of retroviruses, so called because they reverse the usual biological process and cause infected cells to translate the viral genetic material, RNA, into another form, DNA (Whiteside & Fitzsimons, 1992).

After entering the human host, HIV attacks certain cells of the immune system, in particular a subset of white blood cells called T4-lymphocytes (also known as helper T-cells) that play a crucial role in the co-ordination of the immune response (Palloni & Glicklich, 1991). Once the HIV has established itself with a T-lymphocyte, the virus is capable of altering the normal functioning of the cell, and

induces the T-lymphocyte to produce more human immunodeficiency viruses at the total expense of antibody protection (Whiteside, 1990). The body mounts a defense against the invading virus by producing antibodies, but in the long run and for reasons not yet understood, the response is ineffective. The target cells, particularly the T-4 lymphocytes, are functionally impaired or destroyed; and the body's defenses are progressively disabled. The outcome is an increased vulnerability to a variety of opportunistic infections caused by certain viruses, bacteria, fungi or parasites that would not normally cause disease in healthy persons (Palloni & Glicklich, 1991). Typical symptoms appear, such as chronic fatigue or weakness, severe and sustained weight loss, excessive or persistent swelling of the lymph glands, diarrhea and often deterioration of the central nervous system to the extent of dementia. This cluster of conditions is often referred to as "AIDS- related complex" (ARC). Full blown AIDS includes these symptoms and opportunistic infections or cancers such as the skin cancer Kaposi's sarcoma and certain lymphomas (Whitehead & FitzSimmons, 1992).

History has shown that it is extremely difficult to develop protective vaccines against organisms like HIV that can mutate quickly and can present constantly changing antigens to the immune system (Gorman, 1992).

2.2.1 Transmission

HIV is a fragile virus that cannot pass through intact skin. Infection can only occur if infected body fluids, particularly semen, vaginal fluids or blood, enter the body (Arendse, 1991). The virus is transmitted in three main ways. Most commonly, it is passed from person to person through sexual contact, either homosexual or heterosexual. In Africa, 80-85% of transmissions occur through heterosexual vaginal intercourse (Larson, 1990). The virus can also be transmitted via blood, during transfusions or by the sharing of contaminated needles and the accidental injuries of needle sticks to health care workers.

HIV infection is increasingly also passed from mother to infant before or during birth. In developing countries, about a third of children born to infected mothers are actually infected themselves, in developed countries, the proportion is lower. The transmission rate appears to depend on social class, access to health care, and health status and stage of infection of the mother (Whiteside & Fitz Simmons, 1992).

The virus can apparently not be transmitted through the bites of mosquitoes, coughing, sneezing, and the normal sharing of household utensils or through other casual contacts, such as in schools or in the workplace (Arendse, 1991).

2.2.3 Physiological Reaction

There are a number of physiological stages that a person will pass through once infected. Immediately after infection, there is a period (the so called window period) during which the person is infected and infective but does not have sufficient antibodies to be detectable through laboratory testing. This period is known as the seroconversion phase (Sheridan & Radmacher, 1992). This is followed by the phase during which the antibodies are detectable, where the person is healthy but infective, and the virus is replicating and beginning its attack on the immune system.

This second phase, from seroconversion until symptoms actually appear is known as the latent phase. It is generally accepted that the mean time will be seven years or longer. This is followed by the onset of the disease, possibly, initially through "AIDS related complexes" (ARC) and then full-blown AIDS ending in death (Whiteside, 1990).

In the absence of Anti-retroviral treatment (ART), full-blown AIDS is almost inevitable and therefore infection is fatal. ART changes the face of AIDS into a chronic disease. The emotional reaction to infection is therefore as severe as the diagnosis of any fatal illness. The severity is increased by the fact that the patient

is usually relatively young, it is a sexually transmitted disease and there is the expectation of an unsympathetic response from medical personnel and the community (Tilley, 1990).

2.2.4 Psychological Reaction

According to research conducted in Tshwane by Mokhoka (2000), after being diagnosed with HIV, the women she interviewed went through different emotions. The initial reaction was shock and disbelief as it was very difficult for them to accept the fact that they were having the virus in their bodies.

Immediately after a person is diagnosed with HIV, they consequently think about death. From that moment, that person will also be grieving and mourning some loss, which can be loss of life associated with anticipation of death, or loss of time as a result of the now limited life span (Mokhoka, 2000).

Westbrook and Viney (1982) stated that anger, as a psychological reaction to the onset of chronic illness, is often generated by feelings of frustration associated with the illness. As stated by Mokhoka (2000), anger seems to be mainly directed at the people who were thought to be responsible for infecting them. The difference in verbalising and admitting to these feelings of anger seemed to be related to the type of relationship between the women and the person who possibly infected them. Simos (1979) views anger as an integral part of the grieving process.

The emotional reactions also included feelings of self-blame and guilt at being infected. This type of emotional response is common in women, due to the common perception that if they are infected with HIV, they have to be promiscuous (Bennett, 1990). Guilt feelings stem from the thought of dying and leaving one's child behind. These feelings can account for much of the pain of the process of mourning (Simos, 1979).

Mokhoka (2000) stated that upon HIV diagnosis, feelings of hurt were also prominent with the participants from her research. She further stated that thinking about the children and what will eventually happen to them when their mothers are no longer alive, was very hurtful to the women she interviewed. The thought of bringing shame to their families when the family knows the news was also hurtful.

According to Tilley (1990), a patient, in coming to terms with the positive HIV diagnosis often experiences three psychological phases, which are broadly parallel to the physiological phases experienced.

- The first phase is called the initial shock phase. A critical time in the patient's life, characterized by some or all of the following: numbness, blankness, automatism, panic attacks, disordered thoughts and grandiose altruistic expressions. The person frails around for a while until the second phase.
- The second phase, the adaptive phase, consists of denial, depression and aggression, sublimation and acceptance. During the denial stage, the patient insists that the diagnosis is incorrect, and may try consulting other doctors. HIV infected people often adopt a position of depression or aggression, or may become hopeless, reaching an almost paranoid level, feeling scrutinized by friends, neighbours, and colleagues. The most severe degrees of depression and aggression occur when patients do not disclose their status to anyone. The patients who adjust best are those who become positively preoccupied with the infection. They develop an altruistic commitment to assist other AIDS sufferers. Part of the adaptive phase is bargaining and acceptance, which is often seen when the immune system has deteriorated sufficiently to allow the first opportunistic infection, associated with entering the AIDS related complex phase of the illness. An attitude of acceptance implies that whatever the stage of the

infection, the person acts rationally, feels in control to the extent that it is possible, accepts the best help that is available, maintains and develops responsibilities in relationships, plans appropriately for both the present and the likely future. Generally these people maintain a sense of purpose and meaning in their lives. The last phase is the exhaustion phase, which coincides with full-blown AIDS and ultimately death.

2.3 HIV related stigma

Theoretically, stigma can be defined as the imposition of a special, discrediting and unwanted mark on a person or a specific category of persons in such a way that they are looked at as fundamentally and “shamefully different”. The mark is imposed on people who have or are believed to have a distinctive status (UNAIDS, 2002).

Stigma is as old as history and a universal concept. The origin of the word ‘stigma’ is Greek and refers to the physical mark made by fire or with knives on individuals considered outsiders or inferiors. Today, the physical marks have gone, but stigma remains, attached to one or more factors, such as age, gender, ethnicity, religious belief or sexuality discredited by community perception (Kalichman & Simbayi, 2004).

Stigma, defined as “deeply discrediting” attributes in the landmark study by Ervin Goffman (1963), is applied by society and borne or possessed by groups and individuals. Stigma may be associated with specific acts, such as adultery or criminal behaviour, with inherent qualities such as sex, or skin colour, or with quasi-inherent qualities, such as religion or nationality. Some diseases and other health conditions often lead to stigma, affecting particularly people with mental illnesses and physical disabilities. In addition, stigma is sometimes associated with social stereotypes, that are sometimes positive, or sometimes negative, “short-hand” images that we all use to identify strangers and which determine our

reactions to them (UNAIDS, 2002). It is not the quality that is inherently bad, but it is the interpretation given to the situation that makes it negative.

Stigma is a means of social control, defining social norms and punishing those who deviate from the norm. At the heart of stigma, lies the fear that those who are stigmatized and threaten society. Underlying that fear is often ignorance; such as ignorance of the way the life of HIV/AIDS stigmatized groups or ignorance of the realities of sexual behaviour or the way in which diseases spread (UNAIDS, 2002).

The word stigma is used by social scientists more than the general public. In English, everyday speech, it has been replaced by such words as sexism and racism, which carry related, but different meanings, while in some societies, some stigmas have weakened. Lower caste remains a marker of stigmas in Indian culture, women are stigmatized in many societies and homosexual men are still the subject of ridicule and violence in many parts of the world (UNAIDS, 2002).

Although the concept is negative, stigma can have positive consequences. It can create a sense of community among stigmatized individuals, motivating them to support each other and make changes that will improve their lives (UNAIDS, 2002). Even though stigma may appear constant, it is more accurately described as a process (Herek, 1999). New stigmas arise and others fade as changing knowledge and power structures lead to new hierarchies and social norms. Sex between older men and pubescent boys was once acceptable in many societies around the world, but is now almost universally condemned. The stigma against Jews in many Western societies is considerably weaker than it was a hundred years ago. Thus the form and intensity of HIV/AIDS related stigma continues to fluctuate (Herek, 1999).

2.3.1 Discrimination

The original meaning of “discriminate” was to note differences. Over time, however, the word has come to mean to perpetrate an unjust action or inaction against individuals who belong, or are perceived to belong, to a particular group, in particular stigmatized groups (Lachman, 1995). Discrimination can be legislative, enshrined in law or policy, or community actions or inaction in less formal contexts, such as the workplace, social settings such as a marketplace, sports centre or bar.

Stigma and discrimination exist in a vicious circle. Stigma allows or encourages discriminatory attitudes. These attitudes are often reflected in discriminatory behaviour that results in acts of discrimination. These acts of discrimination again draw attention to or increase stigma (Lachman, 1995).

2.3.2 Felt and Enacted Stigma

Attempts to analyze stigma and discrimination have led to narrower definitions that are not always universally understood, such as the distinction between “felt” and “enacted” stigma (UNAIDS, 2001). Felt or personal stigma, which has also been referred to as self-stigmatization and as fear of stigma, refers to the expectations of stigmatized individuals of how others will react to their condition. Felt stigma leads people to hide their stigmatizing condition, if possible, which can limit the extent to which they experience discrimination. Meanwhile, enacted stigma is defined as the actual experience of stigma and discrimination (UNAIDS, 2001).

However, while “felt stigma” is a useful term that describes internal perceptions of stigma, “enacted stigma” is no more than an alternative term for discrimination. Furthermore, it can lead to confusion since it is the individual outside the social norm who “feels” stigma, but the individual or institution inside the social norm that “enacts” it- i.e. discriminates (UNAIDS, 2001). In other words, felt stigma is internal; how people outside the social norm perceive their status, while enacted

stigma is external; how the same people experience discriminatory acts (UNAIDS, 2001).

2.3.3 Stigma and HIV/AIDS

Stigma has long been associated with diseases that provoke strong emotional responses through their association with disfigurement, such as leprosy, polio and cholera. As the cause of both disfigurement (wasting syndrome, Kaposi's sarcoma etc) and death, HIV/AIDS provides fertile ground for stigma to take root.

HIV related Stigma increases where there is ignorance and misconceptions about transmission of the virus leading individuals and communities to fear casual contagion through such actions as shaking hands, coughs and sharing eating and toilet facilities (Paterson, 1996).

Disease related stigma could be reduced by education. A consistent finding in studies is that people who have little knowledge or are misinformed about HIV transmission are much more likely to hold discriminatory attitudes than those who are well informed. In other words, people who are aware that casual contagion is impossible are less likely to hold negative attitudes towards people with HIV/AIDS (Herek, 1999).

A weakening of the association between HIV/AIDS and death also reduces stigma. Anecdotal evidence from several communities suggests that discrimination becomes lower where people with the virus have access to the antiretroviral and other drugs that prolong life and make disfigurement less likely (UNAIDS, 2002).

However, while some sources of prejudice fall away, others remain. HIV/AIDS is also linked to long-standing stigmas of sexual misconduct and in some communities, illicit drug use. People with HIV/AIDS are often believed to have deserved what has happened by doing something wrong; men who become

infected may be seen as homosexual, bisexual or as having had sex with prostitutes, while women with HIV/AIDS are viewed as having been sex workers (UNAIDS, 2002).

HIV related stigma may well be the greatest obstacle to action against the epidemic, for individuals and communities, as well as political, business and religious leaders. An all –out effort against stigma will not only improve the quality of life of people living with HIV and those who are most vulnerable to infection, but meet one of the necessary conditions of a full scale response to the epidemic (UNAIDS, 2001).

HIV/AIDS related stigma starts as soon as information (accurate or not) regarding a person's serostatus is known. It is the process whereby the person is viewed in many different ways, all of them negative and judgmental soon after he/she is known or suspected to be HIV positive (UNAIDS, 2002).

In HIV/AIDS, the essence of stigma is a mental and social reaction closely related to many factors, including culture, personal and social fears, denial, misconceptions and myths about the epidemic. Stigma has been described as a quality that “significantly discredits” an individual in the face of others. It also has important consequences for the way in which individuals come to see themselves. Importantly, stigmatization is a process of devaluation (UNAIDS, 2002). Some of the misconceptions related to HIV include:

- HIV is God's punishment, and a person living with HIV has sinned or is dirty. People are described as guilty (mothers or adults) and others as innocent (children).
- Some believe that they can get HIV through casual contact. This myth has led to children living with or affected by HIV being prohibited from attending school due to fears that they will pass on HIV to the other children.

-
- If someone insists on using condoms, some people assume that that person has HIV.
 - HIV only happens to some people such as gays, black people, poor people and migrants.
 - Some employers believe that people with HIV are sick, unproductive and will burden their companies. Colleagues may refuse to share office facilities with someone living with HIV for fear of getting infected.
 - Some communities and families believe that someone with HIV brings shame upon them. People have been banished, hidden, abandoned and even murdered because they are HIV positive. For fear of this, many people deny or hide their HIV- positive status (UNAIDS, 2002).

It is important to note that, in many settings; issues of sexual nature are not supposed to be openly and publicly discussed. Disclosing one's HIV status would be telling the outside world the consequences of a person's sexual behaviour.

Gilmore & Somerville (1994) state that many metaphors are used that give clear indications about the stigma associated with it:

- ⇒ AIDS is death (both biological and social)
- ⇒ AIDS is a punishment for immoral and sinful behaviour
- ⇒ AIDS is a crime
- ⇒ AIDS only happens to others
- ⇒ AIDS is a horror, terrorizing invader or a demon.

These metaphors appear to be the expression of various perceptions of the epidemic. They lie at the heart of stigma because they provide ideas and things to associate with AIDS. Subsequently, if AIDS is associated with death, crime, punishment, horror, etc, it is quite easy for the general, particularly the uninformed public which unfortunately makes up the majority, to look at infected people as those who carry death, are dangerous criminals, are sinners and

ultimately the incarnation of moral decay in society, thus discouraging disclosure (UNAIDS, 2002).

Many people think that women's fear of violence or experience of past violence with a partner may contribute to the internalisation of stigma. A woman's role and sense of identity with her partner and within her family may also contribute to how she reacts to personal feelings of stigma associated with being HIV positive (Baleta, 1999).

HIV related stigma could arise at community level. The harassing of individuals suspected of being infected or of belonging to a particular group has been widely reported. These are often motivated by the need to blame and punish and in extreme circumstances, can extend to acts of violence and murder. In December 1998, Gugu Dlamini was stoned and beaten to death by neighbours in her township near Durban, South Africa, after disclosing her HIV status (Baleta, 1999).

While HIV is not transmitted in the majority of workplace settings, numerous employers tend to terminate or refuse employment due to the supposed risk of transmission. There is also evidence that if people living with HIV/AIDS are open about their HIV status at work, they may well experience stigmatization and discrimination by others. Pre- employment screening takes place in many industries, particularly in countries where the means for testing are available and affordable, yet it is against human rights (UNAIDS, 2002).

Many reports reveal the extent to which people are stigmatized and discriminated against in healthcare systems. Studies reveal the reality of withheld treatment; non-attendance of hospital staff to patients, HIV testing without consent, lack of confidentiality and denial of hospital facilities and medicines (UNAIDS, 2002).

A survey conducted in 2002 in four Nigerian states involving 1000 physicians and nurses returned disturbing findings. One in 10 doctors and nurses admitted

having refused to care for an HIV/AIDS patient or had denied them admission to a hospital. Almost forty percent thought a person's appearance portrayed his or her HIV positive status, and twenty percent felt that people living with HIV/AIDS had behaved immorally and deserved their fate (UNAIDS, 2002).

A major contributor towards HIV related stigma among doctors and nurses is the fear of exposure to HIV as a result of lack of protective equipment. Also, the frustration of not having access to medicines for treating HIV/AIDS patients adds to the high levels of stigma. Lack of confidentiality has been repeatedly mentioned as a particular problem in healthcare settings. Many people living with HIV/AIDS do not even get to choose how, when and to whom to disclose their HIV status (UNAIDS/WHO, 2002).

2.4 Women and HIV

Reversing economic, social and political biases against women is often presented primarily as a moral or human rights issue (Paterson, 1996). In Europe, the USA and in Latin America, most people still work on the assumption that HIV is an epidemic of homosexual men, or of intravenous drug injectors and their partners. This is no longer the case, especially in sub-Saharan Africa (Paterson, 1996).

Women are biologically more vulnerable than men to all sexually transmitted diseases. Their likelihood of becoming infected with HIV as a result of a single sexual encounter is nearly three times that of a heterosexual male. There is a twenty five percent chance of a man catching gonorrhoea from unprotected sex with an infected woman, a fifty percent chance of a woman catching it from an infected man. This is because the concentration of the virus or bacteria in semen is far greater than it is in the vaginal secretions of the woman, and the vaginal membranes are more permeable than the surface of the penis. They are also more subject to injury. Rape, forced sex or the presence of another sexually transmitted disease greatly increases the likelihood of infection by providing open

sores or lacerations that allow the virus to enter the bloodstream (Paterson, 1996).

The biological vulnerability is often reinforced by cultural, social, and economic factors, many of them outlined above that limit women's ability to protect themselves from infection. Women may want to stipulate fidelity, safe sex, or no sex at all, but where society defines the male partner's needs as paramount, it is very difficult for them to negotiate strategies to protect their health (Paterson, 1996).

Sexual violence plays an important role in the transmission of HIV. Women who are sexually harassed or raped by an infected assailant face the possibility of being infected. Another aspect of sexual violence towards women is with regard to the danger of domestic violence should they refuse sex or insist on condom use or monogamous relationship from their partners. These issues are especially urgent in South Africa in the light of escalating reported incidents of sexual violence (Strebel, 1993).

Since most HIV positive women are known to have been infected through heterosexual intercourse, it is very disturbing to note that most women at risk of infection still find themselves in a position where they can do very little to protect themselves from infection. Supporting the above is the mere fact that the condom (male or female) is still the only physical barrier used for prevention of HIV infection. It is commonly known that this mode of prevention is useless without male co-operation, leaving women without a choice but to depend on men for their own protection (Mokhoka, 2000).

Most societies have a culture of silence around issues of sex and sexuality, and women have to take care to protect their reputations as "proper and reproductive women". Good women are meant to be ignorant about sex and passive in sexual interactions with men. Even if they are well informed, they struggle to be proactive in negotiating safer sex. Meanwhile, female monogamy and male

infidelity and promiscuity are widely accepted as social norms, a situation, which puts married women at risk of infection (Department of Health, 2001).

The traditional norms and expectations of virginity for unmarried girls further increases women's risk of infection because young women are reluctant to ask for information in case they are perceived as being sexually active. The virginity requirement also increases the risk to young girls of rape and sexual coercion because of the belief that sex with a virgin can cleanse an infected man and because of erotic imagery that surrounds the innocence and passivity associated with virginity. A further hazard is the practice of anal sex by some young women in these cultures, in order to preserve their "vaginal virginity". The tearing of the rectal mucosa during anal penetration places these girls at risk of infection (Department of Health, 2001).

Traditional attitudes toward women in South Africa help feed stigma. Stereotypes in which women are seen as subordinates to men socially, psychologically and economically, help shape the way society perceives HIV infected women (Bennett, 1990). Despite women's own HIV/AIDS positive status, these women are still expected to take care of their spouse and their children, resulting in self-neglect. Many South African women infected with HIV/AIDS continue to contend with the day to day struggle of ensuring that their infected and dying spouse and or children are kept clean, receive their medication and receive adequate nutrition while their health continues to fail (Bennett, 1990).

Unfortunately, the increased demand placed on South African women by cultural norms to care for spouse and children, lack of social support from family, friends and society, their own failing health and doomed future outlook, coupled with multiple stigmas associated with HIV/AIDS, cause these women to experience psychological strains such as isolation, fear, anxiety and depression (Bennett, 1990).

Also, for some women with HIV/AIDS, financial assistance is insufficient to adequately meet their needs. For this reason, some of these women turn to men for financial help and do not disclose their HIV status to them because of fear of rejection (Sobo, 1995).

2.5 Disclosure

Disclosure means the giving out of information, which might commonly be kept secret, usually voluntarily, or to be in compliance with legal regulations or work place rules (Southern Africa AIDS Information Dissemination Service {SAFAIDS}, 2003).

At the time of positive test results, women are usually advised to notify their partners about their condition. HIV positive women are also encouraged to obtain regular medical care, to take steps to stay healthy and to make plans about the future of their children as their illness progresses. This can only be attained if they disclose their HIV positive status (Mokhoka, 2000).

Through disclosure of her status, a woman may receive support from her family or others in her social network and may also be able to access available support services. By adequately addressing the emotional, social, and practical sequel of her positive status, she may be more willing to adopt and maintain health behaviours such as cessation of breastfeeding or adherence to treatment regimens (WHO, 2004). It has now been recognized, however, that there are a number of barriers that HIV-infected individuals face when sharing their test results with friends, family and, most importantly, sexual partners (Schmidt & Goggin, 2002).

In a study conducted by Gielen, O'Campo, Faden and Eke (1997) on the experiences of HIV positive women's disclosure, it was discovered that some women are able to disclose their status, while it was very difficult for other women to do so. Some women reported to have disclosed to several people including close family members, partners, and less commonly to a few friends. A significant

number talked to their families only, while only a few told their partners. Most of these women preferred to tell as few people as possible, for reasons such as protection of their privacy and that of their families. Most women reported disclosing their status right away, although some delayed disclosing for periods ranging from a few days to many months.

Reasons for disclosure of HIV status were named mostly following major life events such as the diagnosis of a child and terminal illness in a partner. On the other hand, delaying disclosure was reported to be a result of initial denial about the test results and worry about the impact of the news on others. Fears about disclosure in some women occurred as a result of feared discrimination and rejection, both of which were attributed to people's ignorance about the disease (Mokhoka, 2000).

Gielen et al. (1997) was found that some women did not disclose their status due to fear of a violent reaction. Several women reported being beaten by their partners because they blamed them for infecting them with the virus. Most of the women reported to have experienced support, acceptance and understanding at some point after disclosing their HIV status. Some women reported to have been rejected, abandoned, or shamed by someone in response to disclosure. Descriptions of reactions to disclosure often included references to feelings of shock, anger and sadness.

2.5.1 Common barriers to disclosure

It is evident that the issue of disclosure of a person's HIV positive status is still a difficult aspect due to the stigma surrounding HIV/AIDS, thus making it very difficult for most South African women to disclose. Greenberg (1999) states that some of the reasons for women not to disclose include the following:

- Fear of abandonment and loss of economic support from partners
- Fear of rejection or discrimination

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- Fear of violence
 - Fear of upsetting family members
 - Fear of accusations of infidelity.

On the other hand, Greenberg (1999) states that even though people do not always want to disclose their status; the following factors motivate them to disclose:

- A sense of ethical responsibility
- Concern for partner's health
- Failing health or severity of illness
- Need for social support to cope with the diagnosis to alleviate the stress associated with non-disclosure
- To facilitate HIV preventive behaviour.

2.5.2 The process of HIV status disclosure

Most studies that have examined HIV status disclosure describe the outcome rather than the process of disclosure. Kimberly & Serovich (1996) developed a useful framework to describe the decision-making process for disclosure. The framework outlines a six-step process that includes dilemmas, barriers and decisions at each step.

By expanding our definition of disclosure from the outcome to the process, we can acknowledge and appreciate the numerous factors that influence the decision to disclose, including individual psychological state, personal communication skills and communication patterns, anticipated reactions and individual motivations for disclosure (Kimberly & Serovich, 1996). The identified steps are the following:

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- ❑ The first step is adjustment to the diagnosis. At this stage, individuals may need help adjusting to their diagnosis and reaching a level of personal acceptance.
 - ❑ The second step involves an evaluation of personal disclosure skills. Individuals need to evaluate whether they possess the skills necessary for telling others.
 - ❑ The third step involves evaluating the appropriateness of disclosing to a potential recipient. This process involves taking inventory of one's social network and deciding on an individual basis who should be told, taking into account certain criteria such as role and physical distance from that recipient.
 - ❑ The fourth step is evaluating the circumstances for disclosure. There may be certain circumstances that prohibit disclosure to certain individuals.
 - ❑ The fifth step in the process involves anticipating the reactions of the potential recipients. Individuals need to weigh these anticipated reactions against the anticipated benefits of disclosure to each individual.
 - ❑ Finally, in the sixth step, individuals identify their motivation for disclosure to each recipient (Kimberly & Serovich, 1996).

Disclosure rates to sexual partners increase over time. There are cultural factors that influence the patterns of self-disclosure to sexual partners and other social network members. Women often disclose to multiple categories of people. There is a core group of people who choose not to disclose HIV test results to anyone (3%-10% in the USA and 10%-78% in developing countries). There is also a disparity between intention to disclose and actual disclosure (WHO, 2004).

2.5.3 Positive and Negative Outcomes of Disclosure

According to the World Health Organization (WHO, 2004), positive outcomes of HIV status disclosure to sexual partners are common. Positive outcomes include increased support, acceptance and kindness, decreased anxiety and strengthening of relationships. Negative outcomes include blame, abandonment, anger, violence, stigma and depression (UNAIDS, 2002). While the fear of negative outcomes is a major barrier to HIV status disclosure, the actual rate of reported negative outcomes is relatively small proportion of those who disclosed (WHO, 2004).

The reports of violence following disclosure were more common in studies conducted in the developing world. Women who reported violence as a result of disclosure in the USA tended to be women of low socio-economic status (SES) and women of color with a history of violence in their relationships. HIV-infected women with a sero-discordant sexual partner may be at increased risk for violence following disclosure, because it may be interpreted that she brings HIV into the relationship. Disclosure can lead to increased HIV preventive behaviours including condom use (UNAIDS, 2002).

From this literature, it is evident that most of the information is not specifically based on South African women's experiences, but these reactions are found in different countries. This study aims to produce results based on a South African context in order to provide precise information of how South African women perceive and experience HIV related stigma and to determine the different levels of disclosure.

2.6 Theoretical Framework

The Social Psychology approach will be used as a theoretical framework for this study as it attempts to understand the relationship between individuals, groups, and behaviour, invariably understanding the relationship between HIV related

stigma and the levels of disclosure of women (Baron & Byrne, 2002). Social psychology tries to see how the thoughts, feelings and behaviours of individuals are influenced by the actual, imagined, or implied presence of others. This includes social perception, social interaction, and the many kinds of social influence (e.g. trust, power, and discrimination). Gaining insight into the social psychology of persons involves looking at the influences that individuals have on the beliefs, attitudes, and behaviours of other individuals, as well as the influence that groups have on individuals (Baron & Byrne, 2002). This will aid in gaining understanding of how these HIV positive women experience stigma and what determinants are involved in the levels of disclosure.

Social psychology also tries to understand the influence that individual perceptions and behaviours have upon the behaviour of groups and tries to understand groups as behavioural entities, and the relationships and influences that one group has upon another group (Baron & Byrne, 2002). Stigma occurs within a group of people, and women have to disclose to certain people in this group and not to others, this is already indicative of the significance of the role of social psychology.

In the following chapter, a detailed description of the methodology incorporated in this study will be presented together with information on the sample used.

CHAPTER 3

METHODOLOGY

3.1 Introduction

In this chapter, a detailed description of the method used will be presented. In this specific research, a combination of qualitative and quantitative research was used, thus a rationale is provided for such incorporation. In order to provide a clear idea of how the research results were obtained and analyzed, sampling, data collection instruments, the data collection procedure as well as data analysis will be discussed. In addition, the ethical procedure will be discussed.

3.2 Research Design

The aim of this study is to investigate the experiences of being diagnosed with HIV and HIV- related stigma levels, the decision to disclose or not to disclose as well as the reactions of the people disclosed to. To enable the researcher to explore these experiences, a combination of qualitative and quantitative measures was used. A description of the research methods used will be provided here.

3.2.1 Qualitative Research

Qualitative research is defined as an investigation in which the researcher attempts to understand some larger reality by examining it in a holistic way or by examining components of that reality within their contextual setting (Denzin & Lincoln, 1994). According to Marlow (1993), qualitative research has no statistical methods of inquiry and analysis of social phenomena. It portrays an inductive process in which themes and categories emerge through analysis of data

collected by techniques such as interviews and observations. Qualitative research uses detailed descriptions from the perspective of the research participants themselves as a means of examining specific issues and problems under study (Taylor & Bogdan, 1984).

In this study, a semi-structured interview was used where participants were asked questions about their experiences of being diagnosed HIV+, the stigma related to HIV and behaviour around disclosure of HIV status.

Creswell (1994) proposed five underlying assumptions of qualitative research:

- ❑ The focus is on process and not on product or outcome.
- ❑ The interest is placed on the meaning, i.e. how people make sense of their life's experiences and how they structure their worlds.
- ❑ The mode of inquiry may involve fieldwork, depending on the nature of the study, whereby the researcher physically goes to people's settings, sites or institutions to observe and record the behaviour.
- ❑ The process, meaning and understanding are gained through words and pictures.
- ❑ A researcher builds abstracts, concepts, hypothesis and theories from details, thus making the inquiry inductive.

3.2.2 Quantitative Research

Quantitative research on the other hand is defined as “the numerical representation and manipulation of observations for the purpose of describing and explaining the phenomena that those observations reflect, while qualitative research is used for the purpose of discovering underlying meanings and patterns of relationships (Denzin & Lincoln, 1994).

The aim of quantitative research is to determine how a variable affects another variable in a population. It calls for procedures that use precise definitions, that

use objectivity-seeking methods of data collection and analysis, that is replicable so that findings can be confirmed or disconfirmed, and that are systematic and accumulative (Denzin & Lincoln, 1994).

3.2.3 Combining Qualitative and Quantitative Research

According to Casebeer and Verhoef (1997), combining qualitative and quantitative research is becoming more and more common. Given the complexity of health and health care, the strength of combined research method is particularly helpful.

Common differences usually cited between these types of research are that in qualitative research, the research question investigates meaning, with the key words of enquiry being “what” and “why”, making the approach more flexible with inductive reasoning. Meanwhile, quantitative research is based on statistical analysis and numerical assessment in a highly controlled approach (structured) with deductive reasoning. Also, in qualitative analysis, data reduction occurs in words or themes and data analysis is coded, compared or categorised, whereas, in quantitative analysis, data reduction is numerical, and data analysis is statistical inference or statistical inference (Casebeer & Verhoef, 1997).

It is important to note that these differences are not absolute and are often a matter of degree. However, in general, qualitative research generates rich, detailed and valid (process) data that contribute to in-depth understanding of the context in which the phenomenon under study takes place. Quantitative research generates reliable population-based data and is well suited to establishing cause-effect relationships (Casebeer & Verhoef, 1997).

Therefore, advantages of combining both types of research include the following:

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- ✚ Research development: one approach is used to inform the other, such as using qualitative research, to develop an instrument to be used in quantitative research.
 - ✚ Increased validity: results obtained through one method can be confirmed by means of different data sources.
 - ✚ Complementarily: adding information, i.e. words to numbers and vice versa.
 - ✚ Opportunities for further research: this can be attained by creating new lines of thinking by the emergence of fresh perspectives or contradictions (Casebeer & Verhoef, 1997).

A combination of both the qualitative and quantitative measures would purposely connect the study objectives and methodologies in the context of a single study in order to access a more comprehensive range of information and experience (Denzin & Lincoln, 1994). In this research specifically, the combination will provide comprehensive information on the experiences of being diagnosed HIV positive from a qualitative approach and the measurement of the extent of the stigma and disclosure levels from a quantitative approach thus providing more widespread results.

3.3 Sampling

This study is based on data collected for the Serithi Project where personnel (HIV pre and post test counsellors) from prenatal clinics in disadvantaged areas in Tshwane, Atteridgeville and Mamelodi, were trained to recruit HIV positive pregnant women for the project.

Upon prenatal consultation at the clinics, the HIV counsellors asked the women if they would voluntarily test for HIV. If they tested HIV positive, the counsellors would then inform them about the project as part of HIV post counselling. They would give them the opportunity to decide if they would like to participate in the

project on a voluntary basis and all the women that were approached, agreed to participate. It was explained to them that they had to be interviewed, on regular intervals.

A total of three hundred and seventeen HIV positive, pregnant women were recruited and participated in structured interviews conducted by research assistants. Most of the women identified at the clinics had known their status for an average of four to six weeks. These women were aged between 18 – 35 years, mainly from low socio-economic status, and most of them were unemployed residing in the disadvantaged locations of the city of Tshwane. Seventy nine percent of these women have secondary education as their highest level of education, thirteen percent have tertiary education and the remaining eight percent only have primary education. Eighty two percent of the women used in this study have partners and the remaining eighteen percent have either separated with their partners or are deceased.

The women were compensated with transport money for each interview they attended, provided with lunch, as well as referrals to social workers and medical facilities should an urgent need arise. Another advantage of taking part in the project was that their babies were to be tested for HIV after birth.

3.4 Data Collection Procedure

The personnel of the Serithi project conducted the interviews. They were retired nurses and Psychology and Sociology students from the University of Pretoria. Prior to the interviews, they were extensively trained in interviewing skills and how to complete the questionnaire.

The data was collected over a period of 18 months. Recruitment was done in 4 clinics in Tshwane, and the Serithi project personnel were informed of an appointment by the HIV counsellors who recruited the participants.

At the beginning of the interview, the project was introduced to the participants. They were given the opportunity to decide whether they would like to participate on a voluntary basis. After signing the consent form, the interview commenced. As the nature and content of the interview was quite an emotional one, the interviewers were trained to empathise and appropriately comfort the women, should the need arise.

The interviews were conducted in the participant's mother tongue as the questionnaires were translated into Zulu, Tswana and Pedi to ensure maximum accuracy and validity. Each interview took a maximum duration of two hours and was conducted in private rooms at the clinics where confidentiality was assured. The completed questionnaires were filed and stored in locked cabinets in a secured building. Research assistants entered the data into a database for analysis and anonymity was maintained.

3.5 Data Collection Instrument

As part of a structured interview, the following data to be used in this study was obtained using three stigma scales discussed below.

3.5.1 The following types of stigma were assessed:

- Experienced personal stigma refers to the individual's own attitude towards HIV and the experience of self-blame and how they expect others to react towards them on being aware of the diagnosis (UNAIDS, 2002).
- Perceived community stigma focuses on how they perceive most people in the community to react towards HIV/AIDS (UNAIDS, 2002).
- Enacted stigma is the actual experienced stigma and discriminatory behaviour towards HIV positive people or people affected by HIV (UNAIDS, 2002).

The experience of personal and perceived community stigma was assessed using and adapting items from existing questionnaires (Westbrook & Bauman, 1996). Levels of experienced personal and perceived community stigma were obtained using two scales with 20 questions each. The items are phrased positively and negatively and respondents indicated their level of agreement on a 4-point Likert-type scale: strongly agree, agree, disagree and strongly disagree. In a factor analysis using the data of 150 women three factors underlying the scales were identified: distance in interpersonal relationships, tendency to blame and human rights issues. The Cronbach alfa reliability coefficients for the two scales were 0,79 and 0,82 respectively (Visser & Makin, 2004). Total scores of the scales were calculated in such a way that a high score means the experience of high levels of stigma.

In a further analysis to refine the questionnaire (Kershaw, Makin, Visser & Forsyth, in progress) to measure personal and perceived community stigma, two twelve-item scales were developed, consisting of two factors each: an affect component and interpersonal contact. The Cronbach alfa coefficients of the twelve-item scales were 0,72 for the personal stigma and 0,75 for perceived community stigma. This twelve-item scales were used in the analysis of the relationship between stigma and disclosure.

Enacted stigma was assessed by rating the level of experience of 10 types of behaviour that could be discriminative in interpersonal relationships like avoiding interaction, ending relationships and forms of verbal and physical abuse. The questions were answered on a 3- point scale: “no experience”, “experienced” and “a lot of experience”. A scale score was also calculated for the level of enacted stigma ranging from 20 (maximum score) to 0 (minimum score) where no enacted stigma was experienced.

The experience of being HIV positive was explored through the following open question: “What was your first reaction when you found you were HIV positive?”

To determine the level of disclosure, participants were asked whether they disclosed their status to anyone. This was answered as a yes/no response.

Respondents who disclosed their status to at least one person were asked the following open-ended questions:

- To whom did you disclose your HIV status?
- Why was it that you wanted to tell this person about your HIV status?
- What was this person's reaction when you disclosed your status?
- Why did you decide against disclosing to those you have not disclosed to?
- What gave you the courage to disclose?

Respondents who did not disclose their status at all, were asked the following question:

- Why did you decide not to disclose your HIV status?

3.6 Data Analysis

The results of the three stigma scales are correlated to investigate the relationship between the different stigma measures. The level of disclosure were statistically analysed to determine the relationship between the experience of stigma and disclosure. T-tests are used to determine whether people who disclosed their status experienced a different level of stigma. In this analysis the twelve-item stigma scales were used.

Miles and Huberman (1994) are of the opinion that data analysis of qualitative data consists of three linked sub processes: data reduction, data display and conclusion drawing or verification. These processes occur before data collection, during research design, planning and during data collection as final products are approached and completed.

With data reduction, the potential universe of the data is reduced in an anticipatory way as the researcher chooses a conceptual framework, research questions, cases and instruments. Once actual field notes, interviews, tape transcripts or other data are available, data summaries, coding, finding themes, clustering and writing stories are all instances of further data selection and condensation. While data display is an organized, concise assembly of information that permits conclusion drawing and/or action taking as a second integral part of analysis.

Conclusion drawing and verification involves the researcher in making interpretations and drawing meaning from the displayed data. The range of tactics includes comparison contrast, noting of patterns and themes, clustering, use of metaphors, and use of triangulation, looking for negative cases, following up surprises and checking results with respondents (Miles and Huberman, 1994).

In the data display and interpretation phase content analysis will be used as a technique to quantify manifest (surface-level) descriptive data. Categories will be developed, content will be coded, and category counts be conducted (Allen-Meares, 1985). Content analysis has been defined as a systematic, replicable technique for compressing many words of text into fewer content categories based on explicit rules of coding (Weber, 1990). Since content analysis looks directly at communication via texts or transcripts, and aspects of social interaction and allows for both quantitative and qualitative operations, this method of analysis was considered to be the most appropriate method (Stemler, 2002).

In this research specifically, this approach was incorporated where questionnaires were used and data was analysed using summaries derived from coding. Based on the coding system, themes emerged where interpretations and conclusions were made on the experiences of being diagnosed HIV positive, the decision of disclosure and the different stigma levels.

3.7 Ethical Procedures

The ethical committee of the medical and humanities faculties approved the larger project in 2003. An information leaflet was given to each participant and they signed a letter of informed consent before the interview was conducted.

Participants were promised confidentiality since their names were part of their documentation. Completed questionnaires and data were kept in locked cabinets and no personal detail would be revealed to anyone. Results of the study will be published without disclosing the identification of participants.

The research results derived from the method discussed above will be presented in the next chapter.

CHAPTER 4

RESULTS

4.1 Introduction

This chapter presents the research results. This study constitutes a combination of quantitative and qualitative research. A research sample of three hundred and seventeen South African women who were diagnosed with HIV during pregnancy was used. At the time of the interview, the women had known their status for a period of two to four weeks. The women were aged between 18-35 years and were on average 28 weeks pregnant.

The major areas of investigation in this study involved the statistical (quantitative) measurement of the different types of stigma and an explanation (qualitative) of the women's experiences of being diagnosed with HIV. In addition, issues related to the disclosure of the women's HIV status will also be discussed.

4.2 Quantitative Results

In this section, results of the experiences of stigma will be presented. The levels of stigma were assessed in different categories; namely experienced personal stigma, perceived community stigma and enacted stigma. In addition, the results of the levels of disclosure in terms of the people they decided to, will be given. Lastly, the correlations between the stigma scales and the relationship between stigma and disclosure will be provided.

4.2.1 The experience of stigma

The women completed two scales assessing the personal stigma they experience and the stigma they perceive the community to have towards people with HIV. Highlights from the questionnaires focusing on the experience of HIV+ women are presented in Table 1.

Table1 Personal and Perceived Community Stigma responses

Items: Personal experience of stigma	%	Items: Perceived community stigma	%
Self-guilt and judgment		Self-guilt and judgment	
I feel ashamed	55%	People with HIV should feel ashamed	81%
I have done something to deserve HIV	36%	They deserve HIV	79%
My fault to get HIV	34%	HIV is their own fault	92%
Matter of bad luck	57%	HIV is a matter of bad luck	55%
HIV is punishment for bad behaviour	21%	HIV a punishment for bad behaviour	84%
I feel bewitched	8%	People with HIV are bewitched	38%
Internalized stigma		Interpersonal stigma	
In interaction I feel uncomfortable	73%	Most people: feel uncomfortable with someone with HIV	90%
I think less of myself	22%	Think less of someone with HIV	93%
People are right to be afraid	10%	Are afraid around someone with HIV	86%
Feel less attractive	33%	Not attracted to someone with HIV	84%
Can teach others about life	79%	Can teach about life	68%
Can look after children	93%	Safe to look after children	69%
I deserve praise for handling HIV	97%	People with HIV deserve praise	69%
Understand if people reject my friendship	47%	Would reject friendship	80%
Interpersonal experience of stigma		Interpersonal experience of stigma	
Others do not drink from same tap	51%	Would not drink from same tap	74%
Employers will not hire me	48%	Employers would not hire	73%
Neighbours would not like me living next door	56%	Neighbours do not want someone with HIV living next door	85%
Do not sit next to me in public transport	37%	Would not sit next to someone with HIV in public transport	60%
Human rights		Human rights	
I deserve respect	97%	People with HIV deserve respect	79%
I am no different	77%	Someone with HIV no different	54%

Table 1 shows that thirty six percent of HIV positive women in this study blame themselves, while fifty five percent experience shame and guilt. They believe that other people shun them and seventy three percent of the women feel

uncomfortable when they interact with others. The research established that thirty three percent feel less attractive, while forty seven percent would understand if others do not want to be friends with them. Fifty one percent of the women experience that other people keep a distance from them by not drinking from the same tap and fifty six percent of the women feel that others do not want to live next door to them because of being HIV positive.

The difference between the personal experience of stigma and the perceived community stigma is also shown in Table 1. The HIV positive women perceived the community to have a very negative reaction towards people with HIV, as eighty four percent of the women perceive the community to see HIV as a punishment for bad behaviour and eighty one percent that they should be ashamed of themselves. The majority of the women believe that other people do not want to make contact with people with HIV.

Total scores for the personal and perceived community stigma were calculated in such a way that a high score represents the experience of high levels of stigma. The scale scores were then compared.

4.2.2 Personal stigma

The scale scores for personal stigma were calculated on a scale from minimum 20 to a maximum of 80. The respondents had an average personal stigma score of 43,2. Personal stigma focuses on a person's own feelings about HIV, internalized stigma and self-evaluation.

In Figure 1 the frequency distribution of the personal stigma scale is given.

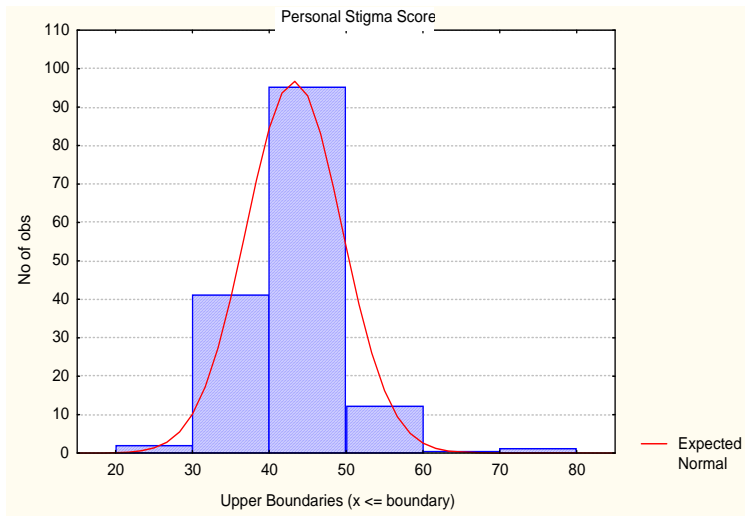


Figure 1 Frequency distribution of personal stigma scores

4.2.3 Perceived Community Stigma

On the same scale the perceived community stigma were much more negative towards people with HIV ($X = 57$). In Figure 2 the frequency distribution of the perceived community stigma scale is given.

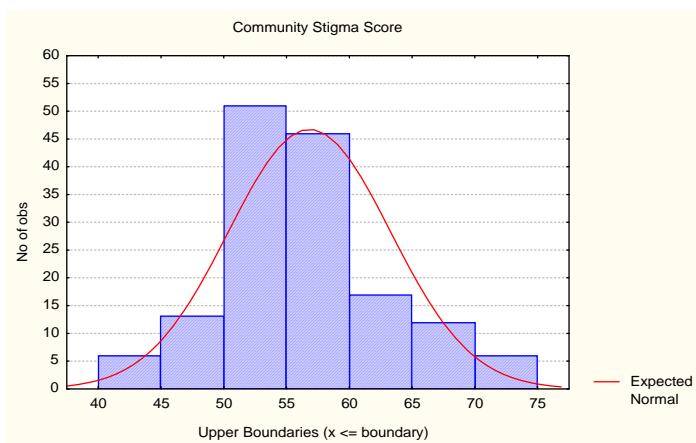


Figure 2 Frequency distribution of perceived community scale scores

4.2.4 Experience of Enacted Stigma

The women reported their experience of enacted stigma in their interactions with other people. This refers to the stigmatizing behaviour and discriminatory actions experienced in interpersonal contact because of the HIV diagnosis. Of the one hundred and ninety three women who disclosed their status, 76,2% did not experience any enacted stigma. Some of the experiences of enacted stigma are given in Table 2 below;

Table 2 Enacted stigma (n=193)

Stigmatizing behaviour and discrimination	
I have lost friends because of HIV	10%
I felt hurt by other people's reaction	25%
People do not touch me	15%
People do not want me around their children	11%
People do not want me to come to their houses	8%
I have been called bad names	13%
I have been physically hurt	5%
I have been threatened with death	4%
My partner left me because of my diagnosis	9%

Based on the reported stigmatizing behaviours, it is evident that some women still experience HIV related stigma and discrimination in South Africa. These behaviours ranged from loss of friendships, rejection, negative reactions, and people not wanting to be near them, calling them bad names, physically hurting them and even threatening to kill them. However, most of the women who reported to have experienced enacted stigma, very few reported serious discriminatory behaviour similar to that of the brutal murder of a South African lady who was stoned to death by her community members for disclosing her status. Even though four percent reported to have been threatened with death,

following disclosure of their status, it is important to acknowledge and report such incidents.

The mean score of the enacted stigma scale was 0, 7 (scale varied from minimum 0 to maximum of 20). There was therefore a very low level of experience of enacted stigma.

4.2.5 Correlation of Stigma Scales

To understand the interrelatedness of the three stigma scores, the correlations between the scores were calculated and presented in Table 3 a, b and c below;

TABLE 3 a Personal and community stigma

	Mean score	Number of Respondents	Correlation	P value
Personal stigma	43,2			
Vs		317	-.106	.060
Community Stigma	57,3			

The perceived community stigma was more negative than the personal experience of the stigma by HIV+ women.

The correlation between the two variables was -0.106 , which is not statistically significant. That means that the two stigma scores are unrelated. No matter how high or low HIV+ women rate their own experience of stigma; they perceive the community to be stigmatizing.

TABLE 3 b Personal and Enacted Stigma

	Mean Score	Number of Respondents	Correlation	P value
Personal Stigma	43,2			
Vs		317	.069	.341
Enacted Stigma	0,7			

The correlation between personal stigma and enacted stigma was 0,069, which also was not significant. The women's experience of stigma thus cannot be associated with physical acts or discrimination that they experience in interaction with others.

TABLE 3 c Community and Enacted stigma

	Mean Score	Number of Respondents	Correlation	P value
Community Stigma	57,3			
Vs		317	.062	.388
Enacted Stigma	0,7			

There was also not a significant correlation between perceived community stigma and enacted stigma. These variables were unrelated.

Based on these results, it is evident that there seems to be no relationship between the three stigma scales, but that they are independent of each other. A detailed description will be provided in the next chapter.

4.2.6 Disclosure Levels

In order to assess how stigma affects the decision to disclose, it was necessary for an analysis of the number of respondents who actually disclosed their status, and the different people they disclosed to.

Out of the three hundred and seventeen women used in this study, only one hundred and ninety three (61%) of the women actually disclosed their HIV status to at least one person, while thirty nine percent did not disclose to anyone they knew. The responses of the women who disclosed are analyzed in this section. Table 4 shows the number of respondents who disclosed to different people.

Table 4 People disclosed to

Person Disclosed to	Number	Percentage of 193 who disclosed	Percentage of sample as a whole
Partner	139	72%	44%
Family members	49	25%	16%
Parents	39	20%	12%
Friends	38	19%	11.9%
In-laws	5	3%	1.5%
People at work	1	0.5%	0.3%

With reference to Table 4, it can be seen that disclosure to partners had the highest prevalence, followed by other family members, then parents and friends, while few disclosed to their in-laws and to people at work. The rationale for the decision to disclose to certain people and not to others will be explained in the qualitative analysis section.

4.2.7 Relationship between Stigma and Disclosure

Since it has already been established that enacted stigma is almost insignificant in this study, only the relationship between personal stigma and perceived community stigma and disclosure was analyzed. In table 5, T-tests were done comparing the stigma scores of women that disclosed their HIV status and women who decided not to disclose. In a further analysis the scores of women who disclosed to their partners and women who disclosed to other family members and friends were analysed. In this analysis, the 12-item stigma scales were used.

Table 5 Stigma scores and disclosure (n=292)

		N	Mean	T value	P value
Total disclosure					
Personal stigma	No disclosure	119	28,40	1,505	0,13
	Disclosure	173	27,48		
Perceived community stigma	No disclosure	119	36,46	0,301	0,76
	Disclosure	173	36,29		
Disclosure to partner					
Personal stigma	No disclosure	153	27,84	-0,067	0,95
	Disclosure	139	27,88		
Perceived community stigma	No disclosure	153	36,41	0,359	0,72
	Disclosure	139	36,18		
Disclosure to others					
Personal stigma	No disclosure	203	28,26	2,065	0,04*
	Disclosure	89	26,92		
Perceived community stigma	No disclosure	203	36,20	-0,835	0,40
	Disclosure	89	36,72		

* Significant at 5% level

Based on the results from Table 5, it is evident that there is not a significant difference in the personal stigma scores of women who decided to disclose their

status and those who decided not to disclose their HIV status if all disclosure is taken into account. A difference was found in women who disclosed their status to their partners and to other family members and friends. Stigma scores did not play a role in women's disclosure to their partners, but did play a role when considering disclosing to relatives and friends. Perceived community stigma scores did not play a role in women's decision to disclose. These scores were found to be high, whether women disclosed or not.

4.3 Qualitative Results

In this section, the results derived from the qualitative analysis will be presented. The aim is to gain a deeper understanding of the experiences of being diagnosed with HIV, reasons for the decision to disclose their HIV positive status to certain people and reasons for non-disclosure. In addition, reactions upon disclosure from the partners, parents and other people who were disclosed to, will also be analyzed. Here, content analysis was used to identify the main themes. Verbatim responses will be provided to clarify what is meant by each theme.

4.3.1 Experience of Being Diagnosed HIV Positive

Upon diagnosis, the respondents experienced various reactions, which will be discussed below. The responses to the question "What was your first reaction when you found out you were HIV positive" were analyzed and the following themes were identified.

TABLE 6 Experience of being HIV Positive

THEME	PERCENTAGE
Fear of death and leaving children	25%
Sadness and helplessness	24%
Passive acceptance	23%
Shock, denial, confusion	19%
Anger towards partner	7%
Self blame	2%

Each of the themes will be discussed below with verbatim examples of each theme.

a) Fear of Death and Leaving Children

Most of the women had a preconceived idea that an HIV diagnosis meant death and that they were going to die in the near future. Their fear of death was based on the slow, degrading and painful death that they had witnessed from other people. Accompanying the fear of death was their fear of leaving their children destitute when they die. Some responses of participants were the following:

“I was so scared; I immediately knew that I was going to die soon, but after a lot of suffering. I was very concerned about who will look after my children when I die”.

“I was scared thinking about how I got this and started thinking that I was going to die and leave my child.”

b) Sadness and Helplessness

This feeling of sadness and helplessness was present with most of the women, the diagnosis was a shock to them, and they were not expecting it to happen to them. There was also a sense of loss, upon diagnosis. They immediately felt that they have lost their life and will be deprived of a normal life, thus bringing about sadness. Some responses were:

“I was badly hurt; it was not easy for me to accept because this is my first relationship with a man. I did not know about this disease”.

“I was not ok, I was so sad; I thought that my life will not be well and that I will be different from other people.”

c) Passive acceptance

Some of the respondents easily accepted their HIV positive diagnosis. This was due to the fact that they were aware of the possibility of being infected, either from their high-risk behaviour or their partner's promiscuous behaviour of which they had no control. Some of the responses of acceptance indicate a passive and almost hopeless way of accepting.

"I was not scared because there are certain things that I could foresee. I was very suspicious about my partner's behaviour."

"I had to accept because I am infected and there is nothing I could do about it."

d) Shock, Denial and Confusion

Shock is an immediate reaction to something unexpected (Dunbar & Mueller, 1998). These women were shocked to a point where it was difficult for them to accept the diagnosis. They thus resorted to a defense and coping mechanism of denial and to pretend that it is not true. Some women were not aware of HIV/AIDS; as a result the diagnosis came as a real shock.

"I was surprised because I did not believe that HIV exists. I usually stay for a long time without sleeping with a boyfriend and I do not sleep around."

"I cannot accept it, I think it is a lie, I don't understand how I could be infected, because prior to planning this pregnancy, I went to a spiritual healer with my partner to undergo cleansing".

e) Anger towards partner

Some women were aware of their partners' high-risk behaviour and some even tried to warn them about the risks of HIV infection. Upon diagnosis, they immediately knew how they got infected and were angry with their partners for infecting them. The following response is an example of this reaction:

"I was very angry at my partner because I trusted him; he has been my only partner. I felt confused; I wanted to leave him but then thought of my kids".

f) Self blame

Some of the respondents admitted that they engaged in high-risk behaviour, despite being aware of the possible consequences of unprotected sex. They ignored the danger of contracting HIV/AIDS through unprotected sex and are now blaming themselves for not taking the necessary precautions. Others blamed themselves for allowing themselves to be infected because they were aware of their partner's high-risk behaviour, but still engaged in unprotected sex with them.

An example:

"I was scared and the first thing I thought was that I am going to die. I knew it was my irresponsibility of having unprotected sex".

Based on the results of the reactions of being diagnosed HIV positive, it is evident that the women presented varying reactions, but they were all aiming towards a shift from the fear of death, shock, hurt, denial or anger towards acceptance of their status. For some of the women that immediately accepted their status, the fact that they were suspecting to be HIV positive and already had a chance of preparing themselves made it easy to accept the diagnosis. Inversely, the women that were shocked, in denial and experienced difficulty accepting their status felt this way as they were not expecting to be HIV positive, thus the difficulty with positive acceptance of the diagnosis.

In the next section, a presentation of the results on disclosure; the decision to disclose or not to disclose and the reactions from the people disclosed to will be presented.

4.3.2 Disclosure

The decision to disclose one's HIV status was one of the major areas of investigation in this study. Out of the three hundred and seventeen respondents, only one hundred and ninety three said that they had disclosed to any other person being, either partners, parents, in-laws, other family members, friends and or people at work. Not only was the decision to disclose of importance in this research, but also the rationale for selecting certain people to disclose to and the rational behind not disclosing to others.

4.3.3 Decision to Disclose

The responses of the participants who disclosed were analyzed based on the question; "what gave you the courage to disclose". This question was only asked to those that had disclosed to somebody they knew. The following is a presentation of the themes that were identified from the qualitative analysis.

a) Trust

The research established that thirty seven percent of the one hundred and ninety three respondents stated that it was easy for them to disclose to the people they disclosed to because they trusted them as they always share secrets. Examples of some of the responses verifying this statement were:

"I trust her a lot. We help each other with many things".

"I trust her; I know she will keep my secret."

b) Need for Support

Research results show that twenty six percent of the respondents said that they needed to disclose because they could not keep it to themselves as they needed as much support and help as they possibly could get. Some of the responses were:

“I told him when I came back from the clinic because I was so hurt and I wanted someone to share the pain with me.”

“I was haunted by the diagnosis and I needed to cough it out so as to feel better”.

c) Practice Safer Sex

Sixteen percent of the respondents disclosed due to the fact that they wanted to start practicing safer sex, as advised by the counsellors. They stated that they also wanted to encourage their partners to go for a test, as they were certain that their partners infected them. Some of the responses were;

“To make him aware and to start using condoms in our relationship.”

“I wanted us to start using condoms and to avoid increasing the infection load”

d) Anger towards Partner

Nine percent of the respondents disclosed to their partners because they were very angry with them for infecting them. An example of some of the responses was:

“I know he infected me that is why I disclosed, so that he must know what he has done

e) Clarification

Eight percent disclosed because they wanted those close to them to understand what is wrong with them and to know what killed them. The following, are some of the responses from the participants:

“When I heard I thought HIV meant AIDS, so I wanted them to know what killed me

“She is the one who will take care of my children when I die”.

f) Acceptance

Four percent had the courage to disclose as they had already accepted their status.

The women disclosed their HIV positive status to certain people for specific reasons. The most prominent reason was that of trust, followed by the need for support. Some women disclosed to their partners due to the fact that they wanted to start engaging in safer sex, and also to promote safer sex to others. Other women were certain that their partners infected them, thus, they disclosed to them because they were very angry with them for infecting them. Some women found it easy to disclose their status because they had already accepted their status.

4.3.4 Reasons for Not Disclosing

The Reasons the women gave for not disclosing to specific people will be analyzed in this section. The following themes were identified for not disclosing to partners and not disclosing to other family members and friends.

4.3.4.1 Non- Disclosure to Partner

Out of the three hundred and seventeen women who participated in this study, one hundred and thirty nine (44%) disclosed their status to their partners for reasons stated above. The other one hundred and seventy eight (56%) respondents did not disclose to their partners and were asked the following question: “Why did you not disclose to your partner?” Themes that emerged from their responses were the following:

a) Not yet ready

26% of the respondents did not disclose their HIV status to their partners because they were still not ready to do so. They wanted to protect them from worrying. They also found it was difficult to disclose to their partners.

b) Fear of rejection

The fear of rejection, blame and partners not supporting them were the reasons why 20% of them not to disclose to their partners.

c) Already knew

The research established that 17% of the women suspected that their partners already knew about their HIV positive status, thus would not disclose to them.

d) Separated or deceased

It was also established that 17% did not disclose to their partners as they had already separated or the partners were deceased.

e) Fear of violence

The fear factor also contributed to non- disclosure, as 16% did not disclose because of fear of violence from their partners as some had promised to kill them if they are HIV positive.

f) Disbelief

Psychological factors such as a sense of disbelief contributed to four percent of the women feeling that their partners would not accept the results by not believing them.

4.3.4.2 Non-Disclosure to Parents

From the one hundred and ninety three respondents who disclosed to somebody they knew, one hundred and fifty four did not disclose to their parents. The following themes were identified as the main reasons for the respondents not to disclose to their parents.

a) Not yet ready

Almost half (41.5%) of the respondents did not disclose to their parents because they felt as if it was rather too soon, they themselves were not ready and were not sure of how their parents would react, but were prepared to disclose to them in the near future.

b) Fear of worsening parent's health

The respondents reported that their parents were already suffering from chronic illnesses, thus 24% of the respondents did not want to worsen their deteriorating health situation by disclosing their HIV status. They anticipated that disclosing would burden their parents.

c) Fear of stigma and discrimination

22% of the respondents did not disclose due to the fear of the stigma attached to HIV, discrimination, and rejection as some were already chased away from home for bringing shame to the family by becoming pregnant.

d) Deceased

Nine percent of the respondents who did not disclose to anyone did not disclose to their parents because they were deceased.

e) Partner's orders

A small percentage, three and a half percent did not disclose because their partners told them not to disclose to their parents.

4.3.4.3 Non-Disclosure to in-laws

A total of one hundred and eighty eight of the one hundred and ninety three respondents who disclosed to someone they knew did not disclose to their in-laws. The responses to the question "Why did you not disclose to your in-laws?" produced the following themes;

a) Fear of rejection and stigma

Half (50%) of the one hundred and eighty eight participants stated their rationale for not disclosing to their in-laws to be the fear of rejection, blame, being chased away due to the stigma associated with HIV.

b) Culture constrains

It was established that 29% of the respondents were waiting for their partners to tell his parents first, since they (women) were not ready to do so and also culture does not allow them to discuss such issues with their in-laws.

c) Fear of negative reaction

Finally, 21% did not disclose to their in-laws because they were scared and not sure of their reaction.

4.3.4.4 Non- Disclosure to Other Family Members

From the one hundred and ninety three respondents, one hundred and forty four did not disclose to other family members. Themes for not disclosing to other family members were the following;

a) Fear of discrimination

It was established that 38% of the respondents did not disclose their status to family members because of fear of discrimination, gossip and blame.

b) Not yet ready

Even though they were not yet ready to disclose to family members, 31% of the respondents stated they eventually would disclose at a later stage when they feel ready.

c) Fear of hurting them

A small percentage of the respondents (15%) stated that it was very difficult for them to disclose because they did not want to hurt their family members.

d) Unnecessary

12% of the respondents stated that they would not disclose their HIV positive status to any family member because they found it to be unnecessary as it was none of their business.

e) Partner's orders

Finally, only four percent of the respondents did not disclose to the other family members because they were ordered by their partners not tell other people about their HIV positive status.

4.3.4.5 Non- Disclosure to Friends

Of the one hundred and ninety three respondents who actually disclosed, one hundred and fifty five, (80 %) did not disclose to their friends for reasons stated below.

a) Fear of stigma and discrimination

Almost half (46%) of the one hundred and fifty five respondents did not disclose their HIV status to their friends due to the fear of discrimination and HIV related stigma.

b) Do not have friends

It was established that 26% of the respondents reported that they do not have friends to disclose to.

c) Not yet ready

Even though they were prepared to disclose to their friends at a later stage, 17% of the respondents felt that they were not yet ready to disclose.

d) Unnecessary

Finally, 11% of the respondents stated that they would not disclose to their friends, as they did not find the need to do so.

4.3.4.6 Non-Disclosure to People at Work

Only one respondent of the one hundred and ninety three respondents disclosed to a person at work, meaning that one hundred and ninety two of the respondents did not disclose for the following reasons:

a) Fear of stigma and discrimination

Almost half (48%) of the respondents did not disclose their HIV positive status to people they work primarily due to the fear of being discriminated against, rejection resulting to loss of the job, and possible change in their attitude based on HIV related stigma.

b) Will never disclose

It was established that 26% of the respondents stated that they would never disclose to their colleagues.

c) Unnecessary

This research also found that 15% of the respondents did not have a specific reason of not disclosing, but felt that it was just unnecessary to disclose to people at work.

d) Not yet ready

Finally, 11% of the respondents were not yet ready to disclose to their colleagues as they were waiting to disclose to their families first.

The main reasons for the women not to disclose were based on the fear of the unknown reactions, which could be of a stigmatising and discriminatory nature. These included; fear of violence and blame, fear of stigma and discrimination, fear of hurting others, fear of negative reactions and rejection. Other reasons for not disclosing were based on cultural constrains where the women were restricted of discussing serious issues, especially stigma related issues before discussing it with their partners or parents first. Finally, some of the women reported that they did not find it necessary to disclose to certain people as the information would be irrelevant and they were not going to help them in any way.

The next section will be a presentation of some of the reactions of the people that were disclosed to.

4.3.4 Reactions after Disclosure

Following disclosure, people reacted in different ways to the news. Different themes emerged from the reported reactions of the people that were disclosed to. These themes varied from denial, shock, indifference, fear and hurt, to

acceptance and assurance of support. Reactions from partners and parents are presented separately as they produced important themes and the reactions of other family members, friends and in-laws were combined. The reactions were categorized under a negative, neutral and positive reaction as shown in Table (9) below.

Table 7 Reactions after disclosure

THEME	CATEGORY	PARTNER (139)	PARENTS (39)	FRIENDS (38), FAMILY MEMBERS (49) & IN-LAWS (5) COLLEAGUES (1)
Denial	Negative	28%	7%	31%
Shock	Negative	17%	16%	27%
Angry	Negative	9%	0%	0%
Afraid	Negative	7%	7%	0%
Hurt	Negative	0%	28%	8%
Indifferent	Neutral	17%	0%	0%
Acceptance	Positive	11%	7%	5%
Supportive	Positive	5%	35%	29%

4.3.4.1 Partner's reaction to disclosure

A very significant number of one hundred and thirty nine of the one hundred and ninety three women disclosed to their partners. The following are the reactions of their partners upon disclosure.

- Denial

The research established that 28% of the women who disclosed to their partners reported that their partners were in denial. Denial is a coping mechanism, associated with misbelieve especially for information that is still too much for them to accept easily (Tilley, 1990). This reaction was categorized under the negative response sphere due to the fact that it discredits reality and implies that there is a negative connotation attached to HIV.

An example of some of the responses given was:

"He does not believe anything I tell him and says that the doctors are lying."

- Shock

It was established that 17% of the partners' immediate reaction was shock; as they did not expect to hear that their partners could be HIV positive. This was quite a strong reaction, as they were not only shocked by their partner's HIV status, but it implied that they too could be infected with the virus.

Example:

"I told him something he did not expect. He was also shocked."

- Anger

Nine percent of the partners were angry because they believed that the women were the ones who infected them, and accused the women for bringing the illness into their relationship. An example of some of the responses stated by the participants was:

“It was a fight, he was very angry, he blames me for destroying his life by infecting him, and so we broke up”.

- Afraid

Fear of death was one of the ideas that immediately came to nine percent of the partner’s minds when disclosed to. This is due to the perception that an HIV positive diagnosis means death, and many had witnessed others die a slow and painful death which obviously terrified them. They were already associating themselves with that sort of death. For example:

“He was very afraid of dying.”

- Hurt

Six percent of the partners were hurt upon the disclosure. It was mainly due to the fact that they felt responsible for infecting their partners. For example:

“He was hurt; he said that's part of life because he knows that he was cheating on me.”

- Indifferent

This response is a neutral response as it is neither positive nor negative. This is indicative that despite the numerous HIV/AIDS awareness programmes, some

people still do not acknowledge the reality of HIV/AIDS, as 17% of the partners were indifferent upon disclosure from the women. Examples of some of the responses relating to indifference were:

“He was cold and distant, seemed not to care about the situation.”

“He just looked at me and turned the other way without saying a word; he acts as if I did not tell him a serious thing.”

- Acceptance

Acceptance of the disclosure was one of the few positive responses, with 11% of the partners having gracefully accepted their partner’s HIV positive status and displayed unconditional acceptance. An example:

“He easily accepted the news as he was already expecting something like that, and he still wants to marry me the civil way”.

- Supportive

Despite the fact that hearing about ones partner’s HIV diagnosis is nerve wrecking as they immediately think about their own HIV status and may instigate negative reactions, five percent of the partners nonetheless promised to support them either emotionally, financially and otherwise. An example of some of the responses stated by the participants was:

“He said he was going to be there for me, he is supportive even now.”

4.3.4.2 Parents' Reaction to Disclosure

Only thirty nine of the one hundred and ninety three women who disclosed to somebody they knew, disclosed to their parents and responded to the question: "What was your parents' reaction when you disclosed to them?"

Based on the responses, it is evident that the reactions of most parents were initially based on shock, denial and sadness. The women felt that even though their parent's initial reaction was negative, they gradually accepted the news and promised to be supportive in every way possible.

The following were some of the responses;

"My parents cried, they were shocked and did not believe it, they never thought that something like this will happen to me".

"They were confused, shocked and upset, but were later understanding and supportive and gave me courage."

4.3.4.3 Family members, friends and in-law's reaction to disclosure

Some of the respondents disclosed to more than one person. Here, forty nine women disclosed to their family members, thirty eight women disclosed to friends, five women to in-laws and finally, one of the women disclosed to a person at work.

As most of the other family members, friends and in-laws that were disclosed to are quite distant socially; the most prominent reaction was that of denial. The respondents report that they found it difficult to believe the news, as they did not know them that well and were quite detached. Others were shocked by the news and very few were hurt. Even though there were negative reactions, most of them were supportive and understanding. The following are some of the reactions:

“He did not accept it because he said that his sister does not run around with men”.

“They sat me down and accepted immediately, they were able to give me support”.

From the analysis of the reactions of the people disclosed to, reported by the women, it was found that the reactions ranged from negative reactions, namely denial, shock, anger, fear and hurt, to neutral reactions of indifference and finally to positive reactions namely; acceptance and supportiveness. It is evident that there are still more negative reactions upon disclosure of one's HIV positive status than positive reactions.

In the next chapter, an interpretation and discussion of the research results presented above will be provided and integrated with findings from previous research.

CHAPTER 5

DISCUSSION OF RESULTS

5.1 Introduction

This chapter discusses the results provided in Chapter Four. The results include: the experiences of an HIV positive diagnosis, disclosure of the women's HIV status, the reasons to disclose, reasons for not disclosing and reactions after disclosure as well as the experience of various types of stigma. Chapter Five also presents a critical evaluation of the study, conclusion and recommendations for further research.

5.2 Experience of HIV Diagnosis

HIV has become an especially stigmatised illness because of the strong blame and dread it generates, as it is an illness connected to already stigmatised groups and to sexuality. It is an illness that is incurable, contagious, disfiguring, and still, somewhat mysterious. Thus from the time of diagnosis, people confront not only the actual and potential physical devastation that their illness can wreck, but also social constructions that encourage blame and dread in themselves and others (UNAIDS, 2002).

Part of this research included the need to logically assess the sampled women's initial reactions to an HIV positive diagnosis. The respondents stated that their initial reactions included; shock, denial, sadness, fear of death and leaving their children destitute, self-blame, guilt and anger. Even though these reactions are normal and expected psychological responses, they however negatively affect their future plans. (Tilley, 1990).

The majority of the women said that after being diagnosed HIV positive, their minds became flooded with imminent death, some even wanted to have abortions. Their suicidal feelings and thoughts to abort their pregnancies were however, erased by the need to give their children a chance to live and also to care for them after birth. The love for their unborn child therefore played a role in fortifying them to accept and live positively with HIV.

Even though their initial reaction was shock, denial, sadness, hurt, confusion and anger, most of the women gradually accepted their HIV status. These findings concur with research results by Mokhoka (2000) when she interviewed black South African women of Tshwane on their psychological experiences upon an HIV positive diagnosis.

Tilley (1990) supports this finding that on receiving an HIV positive diagnosis, people can develop strong and negative emotional reactions. Tilley further states that these reactions include similar emotions as the ones found in our research; including shock, denial, fear, guilt sadness and a sense of hopelessness.

The women sampled in this research said that their HIV positive diagnosis shocked them, as they were not expecting to be HIV positive. Some of them were not yet ready to accept such news and plunged into a denial phase. On the other hand, some of them believed that there were errors in their diagnosis and opted to be tested several times before they could accept the diagnosis as true.

Ongoing research on HIV impacts on the human mind has established that quite often, people who find out they are HIV positive will handle the news either by denying that it is true or by trying to forget it (Kubler- Ross, 1969). Denial can be helpful; it can give one more time to get used to the idea of infection. However, denial can also cause problems for oneself and others if one still engages in risky behaviour, thereby limiting their chances of getting medical attention (Tilley, 1990).

The women said that with time they began to understand and appreciate that indeed they were HIV positive but this did not drive away their feelings of guilt and sadness. The possibility of infecting the unborn child or compromising the unborn child's life, largely invoked their guilt feeling. They believed that they were going to die soon, leaving their very young and helpless children to suffer. Tilley (1990) further states that it is not unusual for people to blame themselves for illness and to feel that it is a punishment. This guilt can be worsened by society's prejudice and ignorance about HIV and AIDS. The women said that the feeling of sadness results from a sudden realization that one could no longer lead a normal life. They felt that their lives became abnormal as an HIV positive people need to watch their diet and be extra careful not to get re-infected. Based on their knowledge about how HIV positive people they knew that eventually died, the women said that they feared dying a very painful death.

The progression of HIV disease may bring life changes and losses of one kind or another. Sadness is an expected reaction. Fortunately, people can later cope with their condition. Unfortunately, failure to overcome sadness can result in a more serious medical problem called depression (Tilley, 1990).

Depression is characterized by prolonged periods of any of the following: sadness and crying, feeling low or despairing, feelings of guilt and lowered self-esteem, a tendency to see only the negative side of things; also, fatigue, decreased ability to concentrate, loss of pleasure in activities, changes in appetite and weight, trouble sleeping, and, sometimes, thoughts of suicide. (Tilley, 1990). A number of the respondents in this study were experiencing some kind of depression as they too reported to have been depressed prior to accepting their condition.

Although cases of depression were not significant in our research, some of the women suffered from anxiety and depression following the HIV positive diagnosis. Anxiety and depression are exacerbated by poor self-image, lack of

fiscal resources and the lack of opportunities to make choices, which disproportionately affect all women in society (Dunbar & Mueller, 1998).

Although anger was not a prominent reaction in this study, its significance was quite high. The women believed that they had been infected by their partners who made it worse by not listening to their regular warning against risky behaviour or refusal to practice safe sex. Anger often becomes a major emotion after an HIV diagnosis (Tilley, 1990). The women stated that they got angry because their lives were cut short and were also faced with the sudden challenge of having to adapt to a new life.

In what is clearly an impressive ability to come to terms with their HIV status, the women said they eventually managed to overcome their anger, sadness and denial and accept their status positively. These reactions corroborate with Kubler-Ross (1969) who states that upon hearing a diagnosis, the patient goes through five stages. Initially, the patient reacts with a shocked, "No, not me." This denial phase is a healthy stage as it permits the patient and the family to develop other defences. Next comes anger or resentment "Why me?" is the question asked now. "Why my child?" Invariably the blame can also be directed at the doctor, nurses and God. Psychologists advise that this outcry should be accepted and not judged as it a natural reaction to an unwanted and unexpected condition.

The third stage is bargaining, "Yes me, but-" or "If you'll just give me five years, God so that I can get my children through high school." This period is called a period of temporary truce.

Depression can follow where the patient has the courage to admit that it is happening. Finally, comes acceptance. A time of facing the diagnosis and to live with it in a congruent way (Kubler-Ross, 1969).

In this research, the women stated that the unconditional acceptance and support from others made it easy for them to progressively accept their status and start adapting to the situation.

5.3 Disclosure

Disclosure of one's HIV status is not an easy task considering the stigma attached to it (UNAIDS 2002). This research explored HIV positive women's levels of disclosure and the reasons for disclosing or not disclosing. Among other things, the research also aimed to determine what made it possible for some of the women to disclose their status. Reasons behind non-disclosure and analyzed the reactions of the people disclosed to were also assessed.

5.3.1 Levels of Disclosure

Sixty one percent of the women sampled in this research disclosed their HIV-status to at least one person. It was established that in the majority of cases, women were more comfortable to disclose to their partners. Consequently, forty four percent of them disclosed to their partners while sixteen percent disclosed to family members, twelve percent of them disclosed to their parents, while eleven percent disclosed to friends, and only one and a half percent to in-laws and lastly, less than one percent (0.3%) disclosed to people at work. The rationale for such disclosure levels is discussed in the next section, which gives the reasons why disclosure was made to some people and not to others.

5.3.2 Reasons to Disclose

Even though disclosure of HIV status is a controversial issue, it is apparent that disclosure has more advantages than disadvantages especially with regard to treatment possibilities (UNAIDS, 2002). The findings of our research concur with this assertion on condition that the person discloses to someone with a guarantee she will not be stigmatized and also on condition that she receive material and moral support.

Since the women wanted only a few people to know of their status, the women disclosed discreetly. Thus the most prominent reason for disclosing was that of trust. The women felt that they could trust the person they disclosed to, that they would not tell other people of their status.

Most women who disclosed said that they could not effectively deal with the knowledge of their HIV status alone. Therefore, they felt that they needed external support from people that they could trust and be assured of their support. They stated that they needed someone to share their pain with. They said the burden of keeping their HIV status a secret was much heavier than disclosing. They also disclosed in anticipation of getting help and appropriate advice with guidance on how best they could cope with their HIV positive status.

Some of the respondents felt the need to disclose to their partners as this would make the partners aware of the critical need to engage in safer sex, in order to reduce chances of re-infection. The sampled women also wanted their partners to go for testing so that they may both know their HIV status.

Finally, most respondents felt that being HIV positive was an inescapable death sentence. It also meant a long illness that made them incapable of taking care of themselves. These fears motivated them to disclose their HIV status to those close to them from whom they expected to receive moral and material support. It also meant that those they disclosed to would help them take adequate safety measures, should they fall ill.

A closer analysis of the above-mentioned reasons for disclosure shows that a sense of trust, unconditional acceptance, promotion of safer sex and warning others are some factors that made the women exclusively disclose partners and family members and others.

The next section focuses on the reasons why some of the women did not to disclose to certain people.

5.3.3 Reasons for Non-Disclosure

At the time of the interview, thirty nine percent of the women did not disclose their status to anyone with the exception of the research assistants. The women gave different reasons for not disclosing, with the fear of HIV related stigma being the most cited reason.

Fear of rejection and discrimination was rife among the women that did not disclose to anyone with forty eight percent of them fearing that they would be ostracized and blamed for having such an illness and eventually lose that relationship. This preconceived idea was based on the negative remarks and attitudes from the people they were contemplating to disclose to.

Eleven percent of the respondents did not want to disclose their HIV status because of the fear of violence either from their partners, parents, or community at large. This was based on practical examples such as Gugu Dlamini who was stoned to death for disclosing her HIV positive status to members of her community.

Another reason for not disclosing was that the women feared that the people disclosed to would find it difficult to believe them. The other reasons of non-disclosure included a possible rejection of HIV results, coupled with demeaning remarks. This response was mainly associated with partners, where a discussion had previously taken place and the partner seemed to reject any possibility of HIV/AIDS, thus would be difficult for them to accept the news.

Some of the women decided not to disclose due to the fear of worsening other people's health especially their parents, as they were already old and suffering from chronic illnesses like hypertension. The women felt that such news would place an extra burden on their parents. They felt that they would rather protect their parents from worry and stress as such news may instigate ill health. Some

had witnessed how their parent's became terribly affected by their siblings' or relatives' HIV status.

Finally, some of the participants decided not to disclose to people that they were not related to such as work mates. They said that it was unnecessary because they would not benefit anything from disclosing to people such as work mates whom they suspected to later ostracized them or say very bad statements about their HIV status behind their backs.

Some of the women who did not disclose said that they were considering disclosing to someone they knew later on. They felt that they had not yet come to terms with their diagnosis, thus making it difficult for them to expect other people to accept their condition. Their reactions concur with Kimberly & Serovich (1996) who describes the process of disclosure as cited in chapter two of this study.

Kimberly & Serovich (1996) state that the first step towards disclosure is adjustment to the diagnosis. At this stage, individuals may need help adjusting to their diagnosis and reaching a level of personal acceptance. The second step involves an evaluation of personal disclosure skills. Individuals need to evaluate whether they possess the skills necessary for telling others. The third step involves evaluating the appropriateness of disclosing to a potential recipient. This process involves taking inventory of one's social network and deciding on an individual basis who should be told, taking into account certain criteria such as role and physical distance from that recipient. The next step is evaluating the circumstances for disclosure. There may be certain circumstances that prohibit disclosure to certain individuals. Then finally is a process that involves anticipating the reactions of the potential recipients.

The above-mentioned reasons make it clear that stigma was the major reason why most participants did not want to disclose their HIV status. The association of the women's reasons for not disclosing with literature provides an indication that the women are experiencing expected phases.

5.3.4 Aspects impacting on disclosure

Based on the established reasons for disclosure or non-disclosure, the following is a summary of the qualities that comprise of the themes related to the reasons for disclosure or non-disclosure. The first two themes namely 1) *Behaviour Change* and 2) *Responsibility* mainly focus on the reasons for disclosure. The latter, 3) *The Impact of Relationships* and 4) *Knowledge*, mainly focus on the factors affecting disclosure. These themes are then sub divided into sub themes as shown below;

5.3.4.1 Behaviour change

One of the most frequent reasons stated by the women for disclosing their HIV status to certain people was to promote behaviour change. Their reasoning in this regard was twofold. They were aiming to promote behaviour change for their own benefit, as well as for the benefit of the individuals to whom they disclosed.

a) Change of Risky Behaviour:

In some cases disclosure was motivated by the need to live longer as some disclosed because they wanted to stop their partners from engaging in high-risk behaviour. Others disclosed to their friends and relatives because they are aware that these people were engaged in dangerous sexual activities. The respondents felt that by disclosing, their partners, family and friends would be able to reflect on their own behaviour and find appropriate ways of changing their behaviour. Our research analysis also established that these disclosures were important as they were likely going to prevent or at least reduce the spread of HIV. This can be ascertained by the use of condoms, thus promoting safer sex.

b) Testing

A few of the women reported that one of their reasons for disclosing was to encourage, especially their partners to test for HIV. Also, they wanted to emphasize the importance of knowing one's HIV status and receiving counseling, regardless of whether the results were positive or negative.

5.3.4.2. Responsibility

To some of the respondents, disclosure was an obligation as well as a responsibility as they were convinced that their partners, parents and close relatives had a right to know.

The following, are sub themes that emerged under the responsibility category:

a) Conscience and Ethical Obligation:

They stated that they disclosed to their partners because they felt that it was their responsibility to do so. Since they were involved in a sexual relationship with their partners, they felt compelled to disclose their status to them because they wanted to start exercising safer sex. The women were totally convinced that this was the right thing to do.

b) Rights of the Unborn Child:

The emotional issues of the rights of an unborn child emerged as one of the strong motivating factors that made the women disclose their HIV status to others for medical advice. The women felt that the unborn child had a right to a healthy and HIV free life. Accordingly, they sought medical advice on how to take the necessary preventive measures in order to protect the child from being infected during pregnancy and at birth. Some of the women said that they disclosed to their partners because they believed that the father had a right to know the risks his child could face.

5.3.4.3. The Impact of Relationships

The nature of relationships played a significant role in determining whether or not one needed to disclose or not. Depending on how close the relationship was, it was possible to predict the likely reactions of people after the disclosure.

According to social psychology, relationships are defined as interpersonal relations, which can be basic, short or long lasting, founded upon strong emotional ties and a sense of commitment to the other person (Tesser, 1995).

This research revealed that the respondents had varying interpretations of the concept of relationships. Based on their perception of their relationships, the following characteristics were identified to impact on their willingness to disclose:

a) Trustworthiness

Most of the women disclosed to people whom they trusted and were confident enough that they would keep the news a secret.

According to the women's responses, a relationship based on trust meant unconditional acceptance of their HIV status, guarantee that they would not be judged or rejected. Trust also meant assurance that whatever they disclosed would not be told to other people. The issue of secrecy seemed to have a high significance as most of the respondents felt that their HIV status was personal.

The research also sought to establish what the women regarded as positive interaction in a post HIV positive diagnosis phase. The women said that positive interaction included: a relationship where "they feel cared for" loved and protected and where freedom of expression is the norm without the fear of being ostracized. Unfortunately, some of the respondents said that their relationships were characterized by violence, blame, stigma, discrimination and ridicule. This destroyed their self worth and esteem. In such negative relationships women decided not to disclose their HIV status.

b) Support

Some of the women decided to disclose to certain people because of their need for emotional and or informational support. They stated that they were certain that they would get such support from these people. The disclosure was also made to people they believed would empathize with them, provide them with advice on how to cope with their HIV status.

5.3.4.4. Knowledge

The women reported that a major factor that made it easy for them to disclose to certain people was that these people were well informed about HIV/AIDS. This meant that they were accurately knowledgeable about the illness and were free from discrediting misconceptions that would suggest discriminatory acts and attitudes. The most important reason for not wanting to disclose to certain people was women's fear of being stigmatized by others who lack basic knowledge about HIV/AIDS. The fear of stigma was especially prominent when faced with the need to disclose to parents, and other family members and friends. This was also evident in the large number of respondents who did not disclose to family and friends.

This research established that the sampled women invariably disclosed to trustworthy and supportive people. They did not disclose to people with whom they did not have a good relationship as they feared that they would later discriminate and stigmatize them.

5.3.5 Reactions Following Disclosure

Based on the reactions of the people disclosed to, the reactions ranged from negative reactions to neutral reactions and finally positive reactions.

From the positive reactions, thirty five percent of the parents that were disclosed to positively accepted, eleven percent of the partners readily accepted the news

and only five percent of the family members, friends, in-laws, and people at work combined easily accepted the HIV positive diagnosis.

However, it is evident that there were more negative reactions than positive reactions as twenty eight percent of the parents were very hurt and disappointed by the news. The women stated that this disappointment was as a negative reaction as they felt it insinuates blame and judgment. Also, twenty eight percent of the partners did not believe the women when they disclosed to them. They were in denial. Twenty eight percent of friends, family members, in-laws and people at work combined were shocked and thirty one percent were in denial, they refused to accept the news as true. This shows how stigma plays an important role, when one is contemplating whether or not to disclose one's HIV positive status.

Only one neutral reaction was established. This reaction was indifference, as some of the people disclosed to seem to be indifferent about the news. They did not seem to be affected by the disclosure in any way. The women reported that it seemed as if they had not told them of a life threatening illness. This attitude indicates that despite all the awareness programmes of trying to educate people of the seriousness of HIV/AIDS, to a certain degree, these attempts prove to be futile.

Even though only five percent of the partners were supportive, following disclosure, it nonetheless is worth recognition. The women reported that some of the men, who tested at the same time with their partners but were found negative, were very supportive to their female partners who were diagnosed HIV positive. One interesting case in point was that of a male partner who tested negative, but still decided to continue with plans to marry the woman who had tested positive. In addition, some of the women's partners decided to test for HIV following the disclosure of the women's status and were willing to take all the necessary actions to make sure that their health was not compromised.

It was also established that some relationships with partners tended to improve as a result of diagnosis with HIV. This finding agrees with the SAFAIDS (2003) research that established that when one or both partners are infected, both may recognize how much the other means to them and how much it would hurt to lose the other. Other problems develop when partners either, become over protective or deny the seriousness of the illness

Even though there were no reports of physical abuse directly resulting from disclosure, some of the partner's reactions were emotionally difficult. The sample women also experienced emotional harm from seeing how hurt their partners were as seven percent of the partners cried in front of them, expressing their fear of the possibility of being infected as well. Six percent of the partners were so depressed that they could not even eat for days. The women were also emotionally hurt, as twenty eight percent of their partners did not accept their HIV positive results. The denial from their male partners implied that no matter how accurate the results might be, HIV is a condition that is difficult to accept. Also, nine percent of the women said that their partners were angry and blamed them for telling them such news, suggesting that they are the ones who infected them.

These negative reactions no doubt posed problems in the relationship as there were so many things they had to consider and adapt to, making it difficult for the women to effectively cope with their diagnosis.

Even though it was not easy for most parents to believe and accept their children's HIV status, the women reported that they experienced support from them. Some parents promised to take care of them, should they fall ill. This was quite interesting as most of these women feared rejection and blame from their parents, prior to disclosure. Their fears were based on how their parents had always spoken about HIV and their negative perceptions on HIV positive people.

Almost half of the respondents said that they did not want to disclose to their parents because they were not ready. They were not sure of their reaction.

However, following disclosure, their parents tried to strengthen them and gave them support amid the hurt, shock and fear.

In interpreting the positive reactions after disclosure, it must be remembered that thirty nine percent of the respondents did not disclose to anyone, thus the results are based on the sixty one percent of the respondents that had already disclosed. It was those who considered it safe enough that experienced positive reactions.

Following diagnosis with a serious illness, or other similar trauma, most people will turn to their families for support (Westbrook & Viney, 1982). For people with HIV, however, this coping strategy is fraught with dangers. Knowing the high level of HIV related stigma, many worry how their families will react to the news of the diagnosis. Other people with HIV assume, based on statements their relatives have made previously, that their response will be unsympathetic. Others do not tell their families because they cannot deal with their own feelings of shame (UNAIDS, 2002).

Although hiding their illness protects individuals from rejection, it creates other problems. Those who do not tell their relatives, deprive themselves of emotional or practical support that they might otherwise receive from their families. In addition, relationships necessarily become strained when people with HIV cannot discuss some of the most important issues in their lives. For these reasons, most people eventually tell their families of their diagnosis. Families may also reject people with HIV because they fear that they too, will be stigmatized should the diagnosis become known (SAFAIDS, 2003).

This was not the case in this study as the respondents found their parents to be very accommodating of their HIV positive status and wanted to help them in any way possible. According to Bennett (1990), following disclosure, some friendships end immediately. Typically, persons with HIV report that some friends are supportive, come around and understand, but most of them have backed off.

Even when relationships survive news of their diagnosis, however, the dynamics of those relationships can change for the worst, as they often worry about the health of the person who is ill, friends will often change their behaviour in a variety of ways that they believe are in the individuals best interests e.g. asking friends with HIV of their dietary restrictions before inviting them for dinner. Such behaviour rankles because it makes individuals feel that they are no longer equal partners in these friendships. In this research, however, the few friends that were disclosed to were morally supportive and did not display signs of discrimination. This was mainly due to the fact that only eleven percent of the women in this study disclosed to their friends, and was certain that these chosen friends would not discriminate against them.

5.4 HIV Related Stigma

Based on the results derived from this research, it has been established that there seems to be a need to bring out differences between different types of HIV related stigma as they provide varying results. From this study, it is evident that not all stigma types play a role in the decision to disclose. In this research women perceived the community to be stigmatizing towards people with HIV, more than their own stigmatizing views of HIV.

Perceived community stigma refers to how the women perceive the community to stigmatize people with HIV. On the other hand, personal stigma refers to how the respondents perceive HIV and how they may internalize the perceptions of others. Enacted stigma refers to the actual stigma and discriminatory acts experienced by the respondents because of their HIV status (UNAIDS, 2002). These types of stigma may consequently influence their social interaction based on their beliefs on what they think or assume other people think of HIV/AIDS (UNAIDS, 2002).

Fifty five percent of the women in this study felt ashamed of having HIV and relate it to some wrong doing in their lives. They also expected that others would

not want to interact with them. For example, seventy four percent of the women felt that people would not like to drink from the same tap with them, while eighty five percent of the women thought that their neighbours would not like to stay next door to them once they learnt that they were HIV positive.

The women feared and projected stigma and discrimination based on their own beliefs of what people might think and act towards them. It is evident that their perceptions of other people's views were much more negative than how those people later reacted. This indicates a perception that the community always stigmatizes HIV positive people. The women stated that their fear of HIV related stigma from the community is based on lack of social support. This aspect of social support seems to raise an opportunity for further research.

This research produced a significantly low score of enacted stigma, indicating that the women reported low levels of enacted stigma. This could be due to the fact that most of them had been recently diagnosed, thus giving them a short period to observe actual discrimination. It is also vital to mention that the respondents said that they were very selective in their disclosure. One can therefore infer that the selectiveness might have contributed to low levels of enacted stigma or discrimination.

5.4.1 Correlation of Stigma Scales

The possibility of a relationship between the stigma scales was assessed, in order to determine if one type of stigma is dependent on or affects the other. When measuring a correlation between experienced personal stigma and perceived community stigma, it was found that a low negative, non- significant correlation exists. This means that these two variables are largely independent of each other. This indicates that the experience of personal or felt stigma does not affect or is not affected by the perception of the level of community stigma in this research. In other words, no matter how high or low a person's experience of personal stigma is, the level of perceived community stigma is not affected and

vice versa. Most of the respondents, independent of their own stigma levels, perceive the community stigma to be high.

The correlation between personal stigma and enacted stigma was once again not significant. Therefore, the amount of personal or felt stigma and the real experience of discriminatory actions from others towards them were unrelated. The experience of personal or felt stigma is thus not based on the actual experiences they have in the community. The level of personal stigma possibly originates from the person's own perception of HIV and fears they may have that others may discriminate against them.

The same was found regarding the correlation between perceived community stigma and enacted stigma. The research also established that enacted stigma and the perceived community stigma are unrelated. The women's perception of high levels of community stigma does not originate from the actual experiences they have in the community, but stems from the perception they have of the community.

Our findings agree with Scambler and Hopkins (1986) who argued that the perceived stigma often proceeds rather than result from the enacted stigma. They claim that many individuals reduce the opportunities for enacted stigma in order to protect themselves from discriminatory actions. People with HIV therefore fear to reveal their status and may withdraw from society because they expect other people to reject them, sometimes irrespective of the enacted or real community stigma.

This suggests that negative media reports on HIV stem from community's negative perception of HIV, but also contribute to perpetuate this stigma. This is evident in the high-perceived community stigma. When a person is diagnosed with HIV they expect people to react negatively and much of the stigma becomes internalized. Because they expect people to react negatively, they do not disclose their status and only select those people they can trust, to disclose to.

Therefore, they do not experience high levels of enacted stigma (Scambler & Hopkins, 1986).

5.4.2 Relationship between Stigma and Disclosure

One of the aims of this research was to determine if a relationship between stigma and disclosure exists, i.e. if the prevalence of HIV related stigma has an impact on the decision of disclosure of one's HIV status. In this research, there was no difference in the stigma scores of women who disclosed and those that did not disclose when the sample as a whole was used. It was found that personal stigma has an impact on women's disclosure to relatives and friends. Levels of personal stigma did not affect disclosure to partners; this proves that there are other dynamics that are relevant in disclosure to partners. This was also confirmed in the qualitative data.

This indicates that disclosure is not related only to the experience of personal stigma but that there also other factors that influence the decision to disclose, and these factors propose further research.

The qualitative results of the study revealed that the fear of stigma and rejection by others were the major reasons given for not disclosing their HIV positive status. The women did not want to disclose to other people because of the fear of HIV related stigma. It was also established that the sixty one percent of the women that disclosed experienced some form of negative reactions and enacted stigma. This was measured in the form of negative reactions versus positive reactions as well as neutral responses from the people that were disclosed to. Therefore, based on the qualitative results, stigma proved to be a huge contributor to the decision of not disclosing. The other factors found in the qualitative results to play a role in disclosure were responsibility to others and the quality of the interpersonal relationships. HIV positive women decided to disclose to people they trust and were convinced who would support them. Positive

relationships and social support where they feel confident enough could therefore give women the courage to disclose despite their fear of being stigmatized.

Because the relationship between personal stigma and disclosure was only found in terms of disclosure to relatives and friends, it can be concluded that the dynamics of relationships also play a role in decisions to disclose. The relationship and interaction between stigma levels, interpersonal relationships, social support and disclosure need to be investigated since social support may mediate the relationship between stigma and disclosure.

5.5 Conclusion

In conclusion, this research has successfully fulfilled the stated objectives and aims. The aims included a study on the experiences of being diagnosed HIV positive, HIV related stigma and the decision to disclose.

Even though it was found that the women who participated in this study experienced being diagnosed with HIV in varying ways, and that were at different levels of accepting their HIV status, there is some indication that they would go through a process of accepting their status (Kubler-Ross, 1969). Another important factor to note is that despite national efforts to enhance HIV/AIDS awareness, some of the women did not believe in the existence or seriousness of the epidemic, as a result, it became very difficult for them to accept their status. This aspect is however overlooked as it is often assumed that every person in South Africa is knowledgeable about HIV/AIDS.

Instead of analyzing stigma in general, this study assessed the different types of stigma, namely personal stigma, perceived community stigma and enacted stigma. It is therefore evident that further research on people's perceptions and beliefs of other people's behaviours towards HIV positive persons is necessary.

Finally, it would be safe to state that based on the results of this study, HIV related stigma plays a very significant role in the decision to disclose or not to

disclose. Also, the decision to disclose or not to disclose is based on the HIV positive person's personal reasons.

5.6 Limitations of the Study

Despite the fact that this research has yielded remarkable results, there existed some aspects that could have a negative effect on the validity of the study.

Firstly, this research was restricted to women of the African race, from only disadvantaged backgrounds and from a low to middle socio-economic class. Therefore, these results are not representative of all South African women of diverse cultures, backgrounds and socio-economic classes.

The women interviewed were newly diagnosed and they had only known about their HIV status for average two to four weeks and had not yet had ample time to disclose and observe enacted stigma. This could have impacted on the relationship found between stigma and disclosure and the level of enacted stigma experienced.

Also, the interviews were conducted by research assistants and deprived the researcher of the real immediate emotional experience of the women. As part of the interview was qualitative, the researcher was not able to consider the actual body language, facial expression and emotional state of the participants, but had to rely on the notes provided by the research assistants.

5.7 Recommendations

Following the limitations of the study discussed above, the following is recommended for future research:

1. A more diversified sample, in terms of race, age, culture, marital status and geographical location can be used.
2. Active involvement of the researcher in the data collection process.

3. In-depth research of the experiences of an HIV positive diagnosis, stigma types as well as aspects affecting disclosure.
4. In depth analysis of the various factors that can have an impact on disclosure since stigma is not the only factor.
5. A longer investigation period to ensure maximum validity of the results.

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