

**THE PSYCHOSOCIAL EFFECTS OF DISCLOSING A POSITIVE  
HIV DIAGNOSIS: A PRELIMINARY INVESTIGATION**

Submitted by

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## ABSTRACT

The aim and objective of this investigation is to explore, on a preliminary basis, the psychological and social effects on a sample of women of having disclosed their positive HIV diagnosis.

The study was conducted in KwaZulu-Natal, South Africa. A convenience sampling approach was used to collect the sample. Inclusion criteria included female, older than 18, with a positive HIV status. Participants' disclosure of a positive HIV status (defined as having voluntarily disclosed to sexual partners, intimate or immediate family, extended family and or friends) was a key inclusion criterion.

Semi-structured interviews were used in the collection of data. Interviews were audio-recorded and transcribed verbatim. Through collaboration with other trained researchers, the data was analyzed and interpreted using investigator triangulation. The independent clinicians identified and established the categories, themes or recurring processes separately using content analysis. The themes in the transcripts as well as from the literature review were utilized as a guide.

The results of this study suggest that there are various factors that influence whether disclosure of a positive HIV diagnosis takes place, largely based on the initial adjustment to the positive HIV diagnosis, the individual's socio-cultural context and the weighing of potential reactions (whether positive or negative) that disclosing a positive HIV diagnosis can induce. The psychological effects of disclosing a positive HIV diagnosis that were identified in this study were anger, fear of stigma/discrimination, shock and disbelief and a false sense of acceptance of the diagnosis.

The social effects of disclosing a positive HIV diagnosis were satisfaction with support received following disclosure. However lack of partner support as well as experiences with stigma/discrimination were identified following disclosure.

## **DECLARATION**

I, Lindelwa Mkize, hereby declare that the work on which this dissertation is based, is original (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or shall be submitted for another degree at this or any other university or institution for tertiary education or examining body.

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**Lindelwa Mkize**

April 2009

## ACKNOWLEDGEMENTS

- ❖ To the very courageous women who were willing to share their personal experiences with me... Thank you...
- ❖ Noo-noo... Nkonko... My Yami... I am so glad I met you... Mommy is so proud of you and I am doing my best for you to be proud of me... You are my inspiration... because of you, I dare to dream... I love you to infinity and beyond...
- ❖ Mama... Tata... Thank you for all your support and the countless sacrifices that you have made so that I could realize my dreams... I am forever indebted... Ndiyanithanda... even in the times that I fail to show you...
- ❖ Lwazi... Akona... Zama ... Thank you for not giving up on me, even in the times that I had given up on myself...
- ❖ Charl Vorster, My supervisor... Thank you for all that you have taught me throughout this process...
- ❖ Carol Saccaggi... My “co-supervisor”... Thank you for your invaluable input, unwavering support and truckloads of encouragement... Most of all thank you for your friendship...
- ❖ Innocent Myeni... Thank you for getting the ball rolling for me, without asking for anything in return...
- ❖ Sindiswa Shezi... You made it happen and not once, did you complain... Thank you...

- ❖ Shane Govender... Amu Mathebule... You heeded my call when I needed you most... Thank you for your input...
- ❖ Sis' Pat Sibanyoni... Your patience was inspiring... Thank you...
- ❖ Cordell... My companion, my friend... Thank you for teaching me to pray...
- ❖ Yoliswa Shasha... You know what you mean to me... Words won't suffice...
- ❖ Tsutsu and Nkanyiso Zwane... You know what you did and you know what you are to me... Thank you...
- ❖ Stephen Ferreira-Teixeira... You thought I forgot you... Never! Thank you for always putting a smile on my face...
- ❖ Nobuntu Shasha... You remind me to always hold my head up high... Thank you...
- ❖ Gogo Busi Malanda... Thank you for your love and guidance...
- ❖ Bo' & Jordan Ruele... Your love and support made the last lap of this process, that much more bearable... Thank you...
- ❖ God Almighty... Through Your Grace... and throughout all that I achieve, I am reminded that You are not done with me...

## **DEDICATION**

To Yamkela  
*Ndiphilela wena.*

## **CHAPTER ONE**

### **INTRODUCTION**

Worldwide, millions of people are living with the Human Immunodeficiency Virus (HIV). Many of these people are not even aware that they are infected. Every year, millions of people die as a result of Acquired Immunodeficiency Syndrome (AIDS), the syndrome that develops as a result of HIV infection. HIV is transmitted through sexual intercourse, sharing of intravenous needles and mother-to-child infection (Centres for Disease Control, 2008). A positive HIV increases vulnerability to infection from other opportunistic infections such as, sexually transmitted infections (STIs) and Tuberculosis (TB) (Centres for Disease Control, 2008).

The HIV pandemic has had its largest impact in sub-Saharan Africa. This is ascribed to a number of factors, among them poverty, disease-related stigma, as well as social and gender norms (Varga, Sherman & Jones, 2005). In African countries confronted with the HIV and AIDS pandemic, most cases of HIV sexual transmission occur within stable relationships (Brou, Djohan, Becquet, Allou, Ekouevi, Viho, Leroy, & Desgrees-du-Lou, 2007). Research findings emphasize that although the epidemic affects all sectors of the population women are more likely to be infected than men.

In sub-Saharan Africa, women are among those at greatest risk for HIV infection, as their access to HIV counseling and testing services is often limited and defined by social and gender norms that dictate behaviour as well as low socio-economic status (Varga et al., 2005). The leading cause of death in women who are infected with HIV is TB (World Health Organization, 2007). Most women discover their positive status through illness or pregnancy, which usually results in the transmission of the virus to the unborn child. This results in women often being labeled as the ‘spreaders’ of infection (Pembrey, 2007).

The disclosure of a positive HIV status is fraught with difficulties. Unlike other chronic diseases, such as for example cancer, the management of the illness and subsequent disclosure of HIV infection is informed by both individual and societal attitudes and beliefs and perceptions around HIV and AIDS. For a long time HIV and AIDS have been associated with not only homosexuality, but also intravenous drug use and infidelity; largely perceived by society as not only degenerative, but also immoral. HIV and AIDS remain shrouded in both secrecy and shame in some communities, and there is often an internal struggle about whether or not to disclose upon discovery of a positive HIV diagnosis. Disclosure can also affect the quality of close relationships, depending on whether the recipient reacts with concern or disinterest (Derlega, Winstead, Greene, Serovich & Elwood, 2004).

The disclosure of a positive HIV diagnosis to sexual partners has become essential in curbing the spread of HIV infection (Skogmar, Shakely, Lans, Danell, Andersson, Tshandu, Oden, Roberts & Francois Venter, 2006). Some studies have found that women who are HIV positive have greater difficulty disclosing their positive HIV status to sexual partners than do men, as the decision to disclose is likely to be influenced by their evaluation of the positive or negative consequences of disclosure (Kimberly & Serovich, 1996).

Reasons for the disclosure of a positive HIV diagnosis to family and friends may include the desire to preserve honesty in the relationship as well as to gain emotional and social support (Kalichman, Klein, Kalichman, O'Connell, Freedman, Eaton & Demetria, 2007; Sowell, Seals, Phillips & Julious, 2003). The motivation to disclose a positive HIV status to family members or loved ones initially involves an assessment of whom to disclose to, evaluation of the quality of one's relationships, weighing and anticipating potential reactions, and is largely influenced by one's evaluation and perception of a positive outcome (Serovich, Craft & Yoon, 2007; Kimberly & Serovich, 1996). Disclosure may also be a criterion for access to much needed resources and support (Parsons, VanOra, Missildine, Purcell & Gomez, 2004; Sowell et al., 2003; Kimberly & Serovich, 1996).

Some positive consequences of disclosing a positive HIV status can include less social isolation and increased social support. An individual is also able to seek medical information and care, as well as social and mental health care services (Parsons et al., 2004; Sowell et al., 2003; Kimberly & Serovich 1996). This includes access to many treatment programmes and other forms of care such as home based care and specific social grants, which have become dependent on disclosure of a positive HIV diagnosis (Norman, Chopra & Kadiyala, 2007).

For many women negative consequences may also be associated with disclosure. Negative consequences of disclosing a positive HIV status can include disruptions in interpersonal and intimate relationships and the potential loss of otherwise supportive relationships (Derlega et al., 2004). There is thus an initial adjustment period to the positive HIV diagnosis, entwined with the implications of having to live with HIV, followed by a process of analyzing the costs versus benefits of disclosure. This process of adjustment to a positive HIV diagnosis as well as evaluating potential disclosure recipients can induce a great deal of stress and anxiety for the individual (Serovich, Kimberly & Green, 1998).

Studies have shown that a supportive response to disclosure of one's positive status can lessen the effects of depression and stress and boost the immune system in counteracting the physical afflictions associated with HIV (Deribe, Woldemichael, Wondafrash, Haile & Amberbir, 2008; Elford, Ibrahim, Bukutu & Anderson, 2008; Serovich, Kimberly & Green, 1998). The psychosocial effects of disclosing a positive HIV diagnosis play a pivotal role not only in the disclosure process, but also in the well-being of the HIV infected individual. Disclosure of HIV infection not only has a cathartic effect on the individual and the anxiety of having to hide the illness is significantly reduced, especially if the response to the disclosure is positive (Deribe et al., 2008).

Studies have also found that the effects of positive social support influence how one deals with the diagnosis, and the decisions inherent in accessing the necessary care and treatment. A perceived lack of support following disclosure of a positive HIV diagnosis,

especially from a significant other and or family members, can induce depression, which in turn affects the immune system's ability to fight infection, increasing vulnerability to illness (Elford et al., 2008; Serovich, Kimberly & Green, 1998).

This brief introduction highlights the importance of disclosure concerning HIV and AIDS. Disclosure thus becomes a core dilemma for women who learn that they are infected with HIV (Spink, 2009). Many studies documenting women's experiences of disclosure to their partner and or family have reported barriers to disclosure such as: women's fears related to stigmatization, family rejection and accusations of infidelity (Brou et al., 2007; Serovich, et al., 2007; Kimberly, Serovich & Greene, 1995).

These findings put a special emphasis on women and the manner in which they deal with their HIV/AIDS infection and subsequent disclosure. The current research aims to explore, on a preliminary basis, the psychosocial effects of disclosing a positive HIV diagnosis, with special emphasis on women.

In Chapter Two, the appropriate literature is discussed with special focus on disclosure, motivations for disclosure and non-disclosure and the psychosocial implications of disclosing a positive HIV diagnosis. Chapter Three will outline the appropriate research methodology. Chapter Four presents the results and discusses the research findings, while Chapter Five concludes with the final conclusions and recommendations.

## **CHAPTER TWO**

### **LITERATURE SURVEY**

#### **2.1 INTRODUCTION**

This chapter creates a context and provides the theoretical foundation for the investigation. Reviewing existing literature in the researcher's area of interest is an essential process. The function of the literature review is to enable the researcher to determine what is known and unknown in the area of interest (Burns & Grove, 2001).

This investigation focuses on the psychosocial effects of disclosing a positive HIV diagnosis with special emphasis on women. The central focus is on the psychosocial ramifications (whether positive or negative) following the women's disclosure of a positive HIV diagnosis. Before the process of disclosure can be addressed, it is necessary to provide a context for discussion. For this reason, this chapter commences with a brief introduction to the phenomenon of HIV and AIDS, incorporating both a historical and a social description.

#### **2.2 Introducing HIV and AIDS**

HIV stands for the Human Immunodeficiency Virus, which is the virus that causes the Acquired Immunodeficiency Syndrome or AIDS. HIV attacks the immune system, which gives the body the ability to fight infections. It destroys a particular type of white blood cell within the body, known as the T-cells or CD4 cells, which are needed by the immune system to fight disease. HIV is found primarily in the blood, semen or vaginal fluid of an infected person (Centres for Disease Control, 2008).

HIV is transmitted through the sharing of equipment such as needles or syringes during intravenous drug use, having unprotected vaginal, anal or oral intercourse, with multiple or anonymous partners and exchanging sex for money or drugs (Kaiser Foundation, 2007). Transmission of the virus during pregnancy is also increased if the mother is HIV

positive, as she can infect her fetus before and during delivery as well as after the birth through breastfeeding. Vulnerability to HIV infection is exacerbated if an individual has been diagnosed with Tuberculosis (TB), hepatitis, or a sexually transmitted infection (STI) (Centres for Disease Control, 2008; Kaiser Foundation, 2007).

AIDS is the final stage of HIV infection. It can take years for a person infected with HIV, even without treatment, to reach this stage. Having AIDS means that the virus has weakened the immune system to a point where the body has a difficult time fighting infections (Centres for Disease Control, 2008). When a person is in the final stages of an AIDS illness the body is weakened to the point where it is no longer capable of resisting opportunistic infections, and fatality is the inevitable result. The table below describes the stages of HIV/AIDS.

**Table 2.1 World Health Organization (WHO) Clinical staging system for HIV management**  
(Almeleh, 2006, p. 141)

Stages	Description	Time	Physical experiences/symptoms
	<b>Initial infection</b>	0-4 weeks	The patient has no symptoms, and appears well
<b>Stage 1</b>	<b>Seroconversion</b>	4-16 weeks after infection	Many patients have no symptoms. 50-80% of patients have a ‘flu-like’ illness lasting 1-2 weeks. In these patients, symptoms include swollen lymph glands (nodes), high temperature, headaches, sore throat and fatigue.
	<b>Asymptomatic phase</b>	>16 weeks	The patient has no symptoms and appears well. Persistent lymph node inflammation may occur due to large numbers of new lymphocytes being made in the lymph nodes. This stage of the disease may continue for many years.
<b>Stage 2</b>	<b>Mildly symptomatic</b>	+ 4 years	The patient experiences symptoms such as slight weight loss, fatigue, mouth ulcers, skin rashes and itching. Diseases include shingles, and recurrent infections of the upper respiratory tract (mouth, sinuses and throat). These symptoms and infections are categorized as minor and are not life threatening. However, they may be unpleasant and debilitating.
<b>Stage 3</b>	<b>Symptomatic</b>	5 years	The patient is weaker and spends more time in bed. Symptoms such as high temperature, night sweats and diarrhea that last for more than a month. Weight loss increases. The patient may have serious infections such as tuberculosis (TB) and pneumonia. Fungal infections of the mouth and genitalia are common (thrush).
<b>Stage 4</b>	<b>Advanced disease</b>	5-13 years	This is the last stage of the disease when the patient is said to have developed Acquired Immune Deficiency Syndrome (AIDS). Syndrome refers to the collection of symptoms and diseases that characterize advanced HIV infection. By this stage the patient is very unwell, unable to care for his/herself and often bedridden for long periods. Weight loss is profound. The patient will have one or more serious infections or cancers that cause damage to the organs of the body and are potentially life threatening.
OR			
<b>Stage 5</b>	HAART is initiated when patient’s CD4 count is 200 cells/mm	Survival depends on CD4 count and age at baseline	

There are many theories around the origins of HIV in the human population. The earliest known case of HIV, discovered in 1959, was from a blood sample of a man in the Democratic Republic of Congo. It is not known how he became infected (Centres for Disease Control, 2008). In 1999, an international team of researchers reported that a subspecies of chimpanzees native to west equatorial Africa had been identified as the original source of the virus. They believe that HIV was first introduced into the human population when hunters became exposed to infected blood (Centres for Disease Control, 2008).

In the United States of America, in the mid-to late 1970's, male patients who had sex with other males began to present with rare types of pneumonia, cancer and other illnesses. In 1982, public health officials coined the term 'acquired immunodeficiency syndrome' or AIDS to describe the occurrences of these opportunistic infections (Centres for Disease Control, 2008).

Men who have sex with men, injection drug users and sex workers still account for significant proportions of HIV infections. However, HIV and AIDS are no longer limited to these subpopulations. The pandemic currently affects all sectors of the population, and its reach is now global (Kaiser Foundation, 2007). This global impact serves as the backdrop to this study, as it contextualizes the urgent need for greater understanding of all the components that affect the HIV pandemic. Thus, the following section presents various studies and statistics relating to both the international and national impact of HIV/AIDS.

### **2.3 The global impact of HIV and AIDS**

In 2006, an estimated 4.3 million people worldwide became newly infected with HIV, including 530 000 children. In the same year, an estimated 2.9 million people died from AIDS-related illnesses (Kaiser Foundation, 2007). At the end of 2006, 63% of all people living with HIV/AIDS lived in sub-Saharan Africa. Fifty-nine percent of all HIV infected adults were women (Brou et al., 2007). Current estimates show that there are 39.5 million

people living with HIV worldwide. The HIV/AIDS pandemic has already claimed more than 25 million lives, making it the leading cause of death worldwide among those aged 15-59 (Kaiser Foundation, 2007).

These figures portray an HIV infection rate that continues to escalate, leaving fewer working age people to support children and the elderly. Individuals die young during their most productive and reproductive years. In some parts of the world, there are disproportionately fewer women than men, due to HIV mortality. Thus, mortality and growth rates are adversely affected as the pandemic alters the population structure, age and sex distributions of hard hit countries (Kaiser Foundation, 2007).

The HIV/AIDS pandemic has had a significant impact on economic growth, communities, households and individuals in many nations across the world. As HIV/AIDS affects and impacts on various components of daily living, the effects become cumulative, as communities and individuals struggle to survive. The pandemic affects both short and long-term economic growth, as the working-age populations are often the hardest hit, causing huge losses of skilled workers (Kaiser Foundation, 2007). This in turn affects a nation's ability to respond to the pandemic as it reverberates across all service sectors. In several African countries, the sectors that have been hardest hit by the pandemic are the health and education sectors. Teacher shortages have been recorded as AIDS claims the lives of teachers, seriously affecting and compromising the education sector (Kaiser Foundation, 2007).

As HIV infections continue to escalate unabated, so does the demand for healthcare services, resulting in over-strained and overwhelmed public health infrastructures in many developing countries. Also disheartening are reports that in some African countries AIDS causes up to one-half of all deaths among employees in the public health sector (Kaiser Foundation, 2007).

HIV/AIDS' threat to economic, social and political stability for many nations is irrefutable. The majority of HIV/AIDS cases in all regions of the world are people living

in low and middle-income countries. Most new infections and AIDS-related deaths also occur in these countries. Many reports have suggested that HIV/AIDS and poverty are intrinsically linked. In many nations where malnutrition, food insecurity and famine have sapped resources, HIV and AIDS further complicate and exacerbate these existing challenges (Kaiser Foundation, 2007).

These alarming facts attest to the enormity of HIV/AIDS' global impact. They paint a grim picture of the future for generations to come. This glimpse into the scourge that is HIV and AIDS provides insight into some of the challenges that are inherent in the fight against a disease that has the potential to annihilate humankind. Against this backdrop, South Africa's internationally acknowledged status as the seat of the HIV/AIDS pandemic in the world (Noble, 2009) is unsettling. The section below presents a closer look at South Africa's status.

#### **2.4 The impact of HIV and AIDS in South Africa**

A study published by the South African Department of Health (2006) estimates that in South Africa 5.5 million people are living with HIV. This is one of the highest figures in the world. It is estimated that in South Africa there are 1500 new infections a day, 257 000 children are infected with HIV and there are 370 000 AIDS-related deaths a year. The provinces that recorded the highest HIV rates were KwaZulu-Natal, Mpumalanga and the Free State. The figures are alarmingly high and are indicative of a crisis.

Geffen (2006) from the Treatment Action Campaign of South Africa explains the implications of the above statistics. These figures essentially mean that one in ten people in South Africa is HIV positive and three out of every ten women who attend public antenatal clinics are HIV positive. The fight against HIV and AIDS has been marred by controversy, especially with regards to the Government's HIV/AIDS policies. It is not the aim of this research to enter into a debate regarding the validity or otherwise of the policies implemented by the South African Government with regards to this issue.

Instead, some facts are presented to highlight core concerns, without attempting to provide an overarching picture of the entire landscape of HIV/AIDS legislation.

The Treatment Action Campaign, better known as the TAC, was launched in 1998 as a vehicle to campaign for the provision of affordable treatment for all South Africans living with HIV and AIDS. This also included campaigning for quality health-care access for all, and the raising of public awareness and understanding about issues surrounding the availability and affordability of HIV treatment (Friedman & Mottiar, 2004). Conflicts between the TAC and the South African Government over policies regarding the HIV/AIDS pandemic and inadequate access to HIV treatment are well documented. The TAC lobbied that access to the life-saving combination of antiretroviral (ARV) drug treatment for all persons infected with HIV, and access to quality health care are human rights (Mbali, 2005).

As a response to the TAC's vigorous campaigns, in 2003 the South African Cabinet instructed the health ministry to develop a comprehensive HIV treatment and prevention plan; also known as the "Operational Plan". The Government has since begun to roll-out HIV treatment in public health facilities across South Africa. ARV drug roll-out is largely dependent on adequate health care facilities that can sustain demand and ensure adherence to medication (Mbali, 2005). This is unfortunately not the case in many areas across South Africa, as many health care facilities, including clinics, are grossly understaffed with a dearth of the necessary resources required to ensure quality health care.

The highest levels of HIV infection are reported in disadvantaged communities, especially in the informal settlements, suggesting that people living with HIV and AIDS in resource-limited settings are the most vulnerable to opportunistic infections and AIDS-related deaths (Ncama, 2007; Geffen, 2006). The South African Government continues to raise awareness about the HIV/AIDS pandemic through the media and other forms of communication. This is augmented with the establishing of free HIV and AIDS counseling and testing, as well as ARV drug rollout in the public health sector.

However, it would seem that the prevalence of HIV and AIDS in South Africa remains at crisis level and the pandemic continues to pervade our homes and communities affecting those most vulnerable to it. Within the home and community it is women: mothers, daughters, lovers and sisters, who are bearing the brunt of the HIV pandemic. More women than men are infected with HIV (Noble, 2009) and this high infection rate has not gone unnoted by researchers. In the section below, research related to women and HIV/AIDS is presented.

## **2.5 Impact of HIV and AIDS on women**

Earlier in this research, the statistics concerning the alarmingly high rates of HIV infection amongst women were presented. The purpose of this section is to move beyond the statistics to look more closely at these women, to examine their characteristics and to try to account for the high rate of infection.

Most women infected by HIV are women who are involved in long-term relationships, are married or are in committed relationships (Brou et al., 2000). Some women who discover that they are HIV positive remain sexually active and continue to engage in unprotected sexual practices, placing others at risk of infection as well as placing themselves at risk for secondary infections such as sexually transmitted infections (STIs) (Marks, Richardson, Crepaz, Stoyanoff, Milam, Kemper, Larsen, Bolan, Weismuller, Hollander & McCutchan, 2002). This lack of engagement in safe sex practices, especially within a stable relationship, suggests that sexual relations with a regular partner are perceived to be risk free (Brou et al., 2000).

Bungener, Marchand-Gonod & Jouvent (2000) found that there is “a lack of understanding of risk behaviour patterns, ignorance of the sexual partner’s risk behaviour patterns, lack of information on HIV-related symptoms and perceived invulnerability to infection” (p. 542). The authors assert that these are the principal hindrances to women recognizing their “at risk” status, and this may explain why women discover their HIV status much later than men, especially in the African population.

An additional factor increasing women's vulnerability to HIV infection relates to biological facts. Women's bodies are biologically more vulnerable to infection as semen remains in the vagina for a long time after penetrative sex, thus increasing women's chances of infection from any single sexual act (The AIDS Consortium, 2007). The inside wall of the vagina is also thin, making it more vulnerable than normal skin to cuts or tears that easily allow HIV into the body. There is also more of the virus in men's semen than in women's vaginal fluid. This means that, with a sexually transmitted infection, women are at least four times more vulnerable to infection. Women often do not know that they have STIs as they frequently show no signs of infection. Sexual violence also increases women's risk of HIV infection, in that rape or forced sex results in cuts or bruising that increase the risk of infection (The AIDS Consortium, 2007).

Gender inequalities in social and economic status also intensify women's vulnerability to HIV. Women in more affluent sectors of society have become emancipated from financial dependency; however there is still a large percentage of women who are financially dependent on men. This can be attributed to gender stereotypes that encourage men to be providers and women to stay at home and raise families. High levels of unemployment amongst women also contribute to their vulnerability (The AIDS Consortium, 2007).

This imbalance in power and control translates into women's sexual lives, as it prevents women from having the financial freedom to leave abusive relationships. Sexual violence is a common occurrence in many married or committed relationships. Many women are not in a position to ask their male partners to use a condom for fear of men's violent reaction. The chances of contracting STIs are increased, as well as the risk of contracting HIV (Spink, 2009; The AIDS Consortium, 2007).

In a recent pilot study, Dr. Salim Abdool Karim and his colleagues from the Medical Research Council (MRC) of South Africa tested a gel (that can be applied vaginally, without a partner knowing) that aims to protect women against HIV infection when their partners cannot or will not use a condom (Kahn & Frank, 2009).

Three thousand women enrolled for the trial between February 2005 and September 2008. The study found a reduction rate of HIV infection of a third (30%). This falls short of the 33% needed for the trial to be statistically significant, however the results of this trial suggest that there is some hope of one day empowering women to have this option when protecting themselves from HIV infection (Kahn & Frank, 2009).

Despite the glimmer of hope provided by such research, the situation at the moment remains dire. The pandemic has multiple effects on women, which include loss of property if they become widowed and or infected, the added responsibility of caring for sick family members, and sometimes even violence when their HIV status is discovered (Spink, 2009; Solomon & Wilkins, 2008; Kaiser Foundation, 2007). For many women, talking about sexual activity or HIV/AIDS is not easy. Discussions on sex and sexuality are almost taboo within the context of a relationship, especially if a woman is dependent on a man for her livelihood. It becomes difficult to refuse sex, even if they know that they are at risk of becoming infected with either an STI or HIV (Spink, 2009; The AIDS Consortium, 2007).

The above findings are disturbing as they speak to the challenges that women, especially in sub-Saharan Africa, have to face in the struggle to maintain their health and wellbeing within the context of the HIV/AIDS pandemic. It is evident from the above discussion that women are most at risk of HIV infection. This is especially true for women from impoverished backgrounds who, against the backdrop of poverty, unemployment and threats of physical violence, are the most predisposed to HIV infection and illness. In the section below, the discussions move to an in-depth description of TB. TB is one of the leading causes of AIDS related illness and death amongst women in sub-Saharan Africa.

## **2.6 Women and HIV/TB co-infection**

It is estimated that one-third of the 40 million people living with HIV/AIDS worldwide are co-infected with TB. Studies suggest that people with HIV are 50 times more likely to develop TB in a given year than people who are HIV negative. Without proper treatment

90% of those living with HIV, die within months of contracting TB. For many people infected with HIV in developing countries, the first manifestation of AIDS is TB. The majority of the people co-infected with both HIV and TB live in sub-Saharan Africa (Badri, Wilson & Wood, 2002).

Tuberculosis (TB) is a disease that usually attacks the lungs but can affect any part of the body. It is important to note that anyone can contract TB. However, TB shortens the survival span of people with HIV and AIDS in that HIV infection converts the latent TB (where the person does not feel ill) into active TB disease. In the active phase of TB symptoms include a persistent cough that lasts for more than two or three weeks, weight loss, loss of appetite, fever, night sweats and coughing up blood (World Health Organisation, 2007).

In their study done in KwaZulu-Natal, Gandhi et al. (2006) found that low rates of treatment completion place people co-infected with HIV and TB at risk for relapse of TB disease as well as drug resistance. They also found that the prevalence rate of multidrug-resistant (MDR) TB among new cases of TB infection is staggering in the province. The figures range from 1.7% between 2000 and 2002 to 9% between 2003 and 2006. If one considers that in KwaZulu-Natal 80% of people that present with active TB are co-infected with HIV, these findings are disconcerting. Although antiretroviral treatment is likely to reduce HIV-related illness and deaths as it becomes more widely available, it will eventually prove ineffective if efforts are not strengthened towards improving TB programmes at the same time.

According to the World Health Organization (2007), TB infection kills more young people and adults than any other infectious disease and is the world's biggest killer of women. In 2007, it is estimated that 900 million women were infected with TB worldwide, 1 million died and 2.5 million between the ages of 15 and 44 became sick with the disease. Once infected with TB, women of reproductive age are more likely to develop TB disease than men of the same age are. Women in this age group are also at greater risk of becoming infected with HIV. Thus, dual infections are common.

These figures and findings clearly demonstrate that women are more vulnerable than their male counterparts, not only to HIV infection, but also to infection by opportunistic diseases such as TB. Women who are in the reproductive stage of their lives are the most susceptible to illness, especially illnesses resulting from HIV infection. These factors in turn impact on the issue of mother-to-child transmission of HIV.

## **2.7 Mother-to-child transmission of HIV**

Women are tested for HIV more frequently than men are as they tend to interact more with the medical sector, especially during antenatal care where the first opportunity for an HIV test arises. Women are thus often the first member of a couple to discover their HIV status. These women are then counseled to share their own HIV test result and to encourage their partner to undertake HIV testing (Brou et al., 2000).

Studies involving HIV positive women in the 26 to 36 year age group in KwaZulu-Natal reveal that women often discover that they are HIV positive through antenatal care. Pregnant women at clinics are encouraged to undertake an HIV test as the transmission of HIV between mother-and-child is preventable, as long as the mother's positive status is known (Crankshaw, 2007; Almeleh, 2006; Varga et al., 2005). Mother-to-child transmission occurs when an HIV infected woman passes the virus to her baby during pregnancy, labor and delivery or breastfeeding.

Despite the preventable nature of mother-to-child transmission UNAIDS estimates that at the end of 2007, 2 million children (under the age of 15) were living with HIV (Spink, 2009). In South Africa, based on a sample of 33 033 women attending 1 415 antenatal clinics across all nine provinces, the Department of Health (2006) estimated that 29.1% of pregnant women were living with HIV in 2006. It is also estimated that about 60 000 babies are born infected, or are infected through breast milk (Makwabe, 2008). In 2005, an estimated 15.9 % of the population in KwaZulu-Natal was HIV positive with an HIV infection rate of 39.1% in pregnant women (Kroonin, 2008).

These figures indicate that women and children are the most at risk and more susceptible to HIV infection. They also indicate a degree of crisis that implies that urgent intervention is needed to curb infection rates among women, especially the transmission of the virus to the unborn child during or after pregnancy. With the implementation of prevention of mother-to-child transmission of HIV (PMTCT) programmes in Africa, prenatal HIV counseling and testing is offered to many pregnant women.

## **2.8 Prevention of mother-to-child transmission of HIV**

Prevention of mother-to-child transmission of HIV (PMTCT) is a short course of drugs (single dose of Nevirapine) taken by HIV infected women to protect their unborn babies from HIV infection (Kanabus & Noble, 2009). It has been widely reported that single dose Nevirapine, which is relatively easy to administer and inexpensive, causes women to develop drug resistant HIV.

A combination of drugs and single dose Nevirapine helps prevent HIV resistance and significantly reduces mother-to-child transmission. However, it is much more difficult to administer and is expensive thus in resource limited settings in the South African public health sector single dose Nevirapine remains the only practical choice (Kanabus & Noble, 2009).

In 2007, the TAC demanded better maternal health and prevention of mother-to-child HIV transmission from the Gauteng Department of Health, by marching in the Ekurhuleni district, in the Gauteng province. This district has a population of 2.5 million people. The memorandum demanded that HIV testing and counseling should be offered, including giving condoms to pregnant women. They also demanded that women who test positive should be given accurate information on infant feeding options, to enable them to make an informed decision about whether to exclusively breastfeed or use formula milk.

For women who choose to breastfeed, Highly Active Antiretroviral Treatment (HAART) should be given for the duration of the breastfeeding period, and those who choose

formula milk, should be given six months free supply. Included in the memorandum was the demand that women who test positive should be offered CD4 counts. Those with a CD4 count below 350 should be given HAART. Babies who test positive should be placed on HAART immediately, to reduce mortality (<http://www.tac.org.za/community/node/2128>).

Highly Active Antiretroviral treatment or HAART, with the combination of other drug therapies, can suppress viral replication while simultaneously decreasing the viral load to undetectable levels. Adherence to antiretroviral treatment is “associated with improved virologic outcome, restoration of immunologic functioning and improved quality of life” (Mellins, Havens, McCaskill, Leu, Brudney & Chesney, 2002, p. 451). Non-adherence or missing doses can permanently undermine HIV treatment, by increasing viral resistance to antiretroviral treatment and reducing its efficacy (Vyavaharkar, Moneyham, Tavakoli, Phillips, Murdaugh, Jackson & Meding, 2007; Mellins et al., 2002).

With the implementation of HAART, the accessing of treatment and social grants is largely dependent on the HIV infected individual’s disclosure to at least one member of the family or a friend to ensure strict adherence to the regimen. An in-depth discussion of the process of disclosure as well as the psychosocial effects that have been associated with such disclosure follows in the next section.

## **2.9 Disclosure**

Varga et al., (2005) describe disclosure as either voluntary or involuntary. “Voluntary disclosure is the act of divulging one’s positive HIV status through a decision made and undertaken without coercion. Involuntary disclosure occurs when one’s positive HIV status is revealed without the individual’s permission” (p. 952-953). For the purposes of this study, disclosure will be defined as the voluntary disclosure of one’s HIV diagnosis to sexual partners, intimate or immediate family, extended family and or friends.

### **2.9.1 The benefits of disclosure**

Disclosure of a positive HIV diagnosis is an important aspect of coping with the disease and understanding the circumstances surrounding it. It also plays an essential part in changing behaviour, to both prevent HIV and alleviate its impact (Norman et al., 2005; Varga et al., 2005; Sowell et al., 2003). Disclosure can also empower the individual, especially women, to make better reproductive choices as well as garner psychosocial support. Women who have disclosed to their partners may be more likely to participate in PMTCT programmes as well as to adhere to antiretroviral treatment (Deribe et al., 2008).

Positive consequences of disclosure of a positive HIV diagnosis to a sexual partner may include a strengthening of the relationship and mobilizing the couple to deal with the disease in a unified manner, thus adopting safer sex practices (Parsons et al., 2004). The individual is then able to avoid the anxieties of having to hide their positive HIV status, thus lowering their stress and lowering risk behaviours (Elford et al., 2008; Bouillon, Lert, Sitta, Schmaus, Spire & Dray-Spira, 2007; Lam, Naar-King & Wright, 2007; Almeleh, 2006).

### **2.9.2 The costs of disclosure**

It is important to recognize the role that stigma plays. Those who feel ashamed of their positive HIV status are less likely to disclose their HIV status (Parsons et al., 2004). Stigma and a lack of acceptance following a HIV positive diagnosis have been recognized as barriers to disclosure, health care and social support (Ncama, 2007). Fear of being a burden to family members, fear of being identified and labeled as HIV positive and stigma surrounding a positive HIV diagnosis may be some of the factors that come into play in keeping a positive diagnosis a secret (Deribe et al., 2008; Bouillon et al., 2007; Almeleh, 2006).

This is also in keeping with the findings of various studies that disclosure of HIV to significant others may elicit negative responses such as blame, rejection or violence

(Elford et al., 2008; Bouillon et al., 2007; Skogmar et al., 2006). Non-disclosure of a positive HIV diagnosis can frequently be attributed to a fear of negative consequences that may include rejection, blame, abandonment, isolation, verbal and physical abuse and withdrawal of financial support (Kalichman et al., 2007; Sowell et al., 2003). It is against this backdrop that the disclosure process is about much more than having to adjust to an HIV positive diagnosis.

It would seem from the above discussion that dealing with the implications of disclosing a positive HIV status is influenced by the negotiation of fears around anticipated reactions, whether they are positive or negative, following disclosure. However, whom the afflicted person decides to disclose to in accessing much needed support is also important. This is attended to in the next section.

### **2.9.3 Disclosure targets**

Disclosure targets or recipients vary from individual to individual. In the African-American community, particularly with women who are infected with HIV, there is evidence to support high rates of disclosure to sexual partners (Derlega et al., 2004). According to Antelman, Smith, Fawzi, Kaaya, Mbwambo, Msamanga, Hunter & Fawzi (2001), the type and duration of the relationship between the woman and her partner may also influence the decision of whether to disclose or not. Women who have been married for less than 2 years, or those in a co-habiting relationship (of any duration) were less likely to disclose to their partners than those women who had been married for 2 years or longer.

Family members are also frequent disclosure targets. Kalichman et al. (2007) assert that within the family, mothers and sisters are disclosed to about HIV infection more often than fathers and brothers. This is in keeping with a study done in Khayelitsha, Cape Town, by Almeleh (2006), who found that the most common disclosure target in women infected with HIV was the mother. Other disclosure targets, in order of frequency, are brothers, sisters, boyfriends, female cousins and friends. Varga et al. (2005), in their

study on HIV disclosure in Johannesburg, found that out of 93.5% of the sample of women who had disclosed their HIV positive diagnosis, for 70.4% the primary disclosure target was a husband or partner; followed by a secondary disclosure rate of 67.9% to targets who were most often immediate female family members.

The disclosure targets are often chosen on the basis of the quality of the relationship, emotional as well as physical distance, and the type of support needed following the discovery of a positive HIV diagnosis. The tendency for female family members to be selected as disclosure targets more often than their male counterparts, could be attributed to them being viewed as more sympathetic and nurturing (Serovich et al., 2007). According to Crankshaw (2007) women who are infected with HIV, are generally more motivated to disclose to people who will offer support and understanding and people who are known to keep secrets.

When disclosing a positive HIV diagnosis the question of who to disclose to is only one of several factors that play a role in the decision to disclose. Even if a suitable disclosure target is available, an individual might still choose to keep their status a secret, based on other factors. The section below explores some of these factors.

#### **2.9.4 Factors influencing disclosure and non-disclosure**

Kimberly et al. (1995), in their study of the disclosure of HIV in women, found that there is a six-step process inherent in the disclosure process, which may influence the motivation for disclosure or non-disclosure. It is important to note that movement between the steps, as well as time taken for each step, is unique to each individual and their social context.

- **Step 1: Adjusting to the diagnosis**

Personal adjustments to the shock of the diagnosis are made before telling others. This coincides with either the time between testing and re-testing, or between a partner's diagnosis and one's own.

- **Step 2: Evaluating personal disclosure skills**

After reaching some level of being able to deal with the diagnosis, the individual assesses whether they have the necessary skills needed to tell others. A great deal of anxiety is inherent in the above-mentioned step, as the individual does not know how to approach the disclosure targets.

- **Step 3: Taking inventory**

The individual assesses the appropriateness of the potential disclosure target. These center on the quality of the relationship, the role of the disclosure target, as well as the social distance in relation to the discloser.

- **Step 4: Evaluating potential target's circumstances**

The disclosure target may be deemed appropriate; however the target's circumstances such as physical proximity, poor health or personal crises might also prohibit disclosure.

- **Step 5: Anticipating the target's reaction**

Anticipated reactions from the target take three forms: supportive, hostile and ambivalent. When, for example, a hostile reaction is anticipated, disclosure does not take place.

- **Step 6: Motivation for disclosure**

Motivation takes two forms: support and obligation. Support includes the cathartic benefit of disclosure, as well as instrumental support, in terms of acquiring additional information about HIV, and care for children. Obligation includes a sense of duty and a desire to warn or help the other person.

Almeleh (2006) and Derlega et al. (2004) divided their motivations for disclosure or non-disclosure into three categories:

- **Self-focused reasons for disclosure** which include catharsis and seeking help.
- **Other-focused reasons for disclosure** which include duty to inform and to educate others about HIV.

- **Relationship-focused reasons for disclosure** which include being in an emotionally close and supportive relationship.

In examining some of the factors involved in disclosure and non-disclosure in persons infected with HIV, Derlega et al. (2004) postulate that the motivations for disclosure upon discovery of a positive HIV diagnosis centre on the two following factors. Firstly, the **social environment** in which the individual lives. This is inclusive of the cultural attitudes about HIV, and the quality of one's close relationships. HIV disclosure may be inhibited if the individual lives in a community that stigmatizes someone with HIV. Studies have shown that in the public lack of knowledge about HIV transmission is also positively associated with negative perceptions of HIV and AIDS (Serovich et al., 1998).

Secondly, **the individual's social network** which is based on the availability and supportiveness of one's partner, family, friends, health providers as well as the progression of disease (i.e. length of time living with HIV). As HIV progresses, the motivation to disclose may be precipitated by the visible signs of the disease as well as the urgent need for emotional support or material assistance (Deribe et al., 2008; Bouillon et al., 2007).

Most individuals disclose their HIV status when their health is already visibly compromised. People learn of their positive HIV diagnosis at different stages of the disease thus the motivation to disclose may be heavily influenced and informed by the timing of the diagnosis (Deribe et al., 2008; Bouillon et al., 2007). "HIV/AIDS may be perceived as a disease that begins with a seriously compromised health status, that ultimately results in death; because people discover their HIV infection when they are pregnant or sick, and thus only disclose in the later stages of the disease," (Almeleh, 2006, p. 148). Studies have found a correlation between the motivation to disclose a positive HIV status and the progression of the disease.

As the disease progresses and the immune system becomes compromised, a gateway is opened for other opportunistic infections as described earlier in this chapter. At this stage

of the illness, disclosure is more common as the individual is rendered incapable of hiding the illness, resulting in the individual needing care and support (Deribe et al., 2008; Bouillon et al., 2007; Ncama, 2007; Almeleh, 2006). With the progression of the disease also comes deterioration in health and frequent hospitalizations, requiring the individual to explain their illness. If death is imminent, the individual fears that they will require additional help in managing the final stage of the disease; therefore, disclosure is more likely (Serovich et al., 2007).

Petrak, Doyle, Smith, Skinner & Hedge (2001) also found a correlation between HIV disclosure and disease progression. In their sample, they found that 51.6% individuals in the asymptomatic HIV infection stage had disclosed compared to 71.3% in the symptomatic HIV infection stage and 73% at the AIDS diagnosis stage. Motivations for non-disclosure in an individual who is HIV positive may include feelings of being ill-prepared, concerns regarding confidentiality, perceptions of being in good health and possible unhelpful reactions of others, following disclosure (Petrak et al., 2001).

What this essentially means is that the motivation to disclose increases as the disease becomes more visible. Because a person who is infected with HIV can live many years without any signs of illness, the process of disclosure is delayed. What this means is that, as long as an individual who is HIV infected remains asymptomatic and can hide the illness, and until the rewards of disclosing far outweigh the repercussions, disclosure is delayed and or avoided.

In contrast to these findings Serovich et al. (2007) found no correlation between disease progression and the motivation to disclose. They found that the HIV infected individual's motivation to disclose is largely influenced by the weighing of the positive and negative consequences that such a disclosure process would incur.

This section has demonstrated that disease progression resulting from HIV infection can influence both the motivations for disclosure and or non-disclosure. It is important to note that this varies with each individual and is largely influenced by an individual's socio-

cultural context. In the next section the socio-cultural aspects around disclosure are presented.

### **2.9.5 Socio-cultural effects of disclosure**

Disclosure of HIV is also affected and influenced by an individual's socio-cultural beliefs within the context of his or her social sphere. Spiritual beliefs are often closely linked with beliefs about health, disease and behaviour and "some religious practices and beliefs are among the multiple factors influencing adherence to treatment" (Vyavaharkar et al., 2007, p. 677-678). A person's belief about their treatment and disease plays a more important role for disclosure than the actual treatment itself (Skogmar et al., 2006).

This finding is in keeping with a study conducted by the Human Sciences Research Council (2007) in three hospitals providing antiretroviral drugs. The study found that out of a sample of 484 people with HIV, one out of every two people (50%) with HIV in KwaZulu-Natal believes traditional remedies are safer than Western medicines. More than 66% believe that they would not be able to live without traditional medicines, and more than 60% believe that herbs control their HIV rather than antiretroviral treatment (Mthethwa, 2008).

Ashford, 2005 cited in Almeleh (2006) in his study done in Soweto, Johannesburg, found a correlation between HIV/AIDS and witchcraft, in that "common symptoms of AIDS such as diarrhea, persistent cough and abdominal pains, have long been associated with the malicious attacks of witches" (p.147) more commonly known as *ukuloya* [Zulu expression meaning to bewitch or to cast a spell].

Many communities also stigmatize people who are infected with HIV/AIDS. Discrimination is common and includes being unwilling to share eating utensils with someone who is suspected of being infected with HIV/AIDS, name-calling and malicious gossip (Almeleh, 2006). In some communities extreme weight loss is associated with AIDS illness. People believe they are able to identify an HIV infected individual by

observing his or her weight (Nicole et al., 1993 cited in Almeleh, 2006). Having to avoid stigmatizing attitudes from the community, while at the same time accessing treatment, care and support is a tricky path to negotiate for people living with HIV/AIDS.

“In a society with poor tolerance towards people living with HIV and AIDS, the anticipation of negative reactions and internalization of stigma act as barriers to disclosure and furthermore to effective emotional and social support” (Bouillon et al., 2007, p. 93). It is important to note that people are bound by their social context and thus their individual actions, especially with regards to disclosure of a positive HIV diagnosis are a response to their environment (Almeleh, 2006).

Given South Africa’s multi-cultural heritage, interventions in the fight against HIV and AIDS would perhaps better serve HIV infected individuals and those living with AIDS, if the traditional belief system of an individual was better assessed and incorporated in the mode of treatment and or intervention. Interventions should also target the psychosocial implications of disclosing a positive HIV diagnosis as they play a pivotal role not only in the management of the disease but also in the disease prognosis.

#### **2.9.6 Psychological effects and disclosure**

For many women, the transition from the initial discovery of HIV infection, to finding effective ways of coping within their families and communities, can induce psychological distress, especially if they have not disclosed. There are various psychological consequences resulting from both the disclosure and non-disclosure of a positive HIV status.

Fear of discrimination and rejection often leads to people living with HIV and AIDS suffering in silence, which in turn can result in feelings of hopelessness and depression. Depression is marked by the presence of some of the following symptoms: marked functional impairment, morbid preoccupation with feelings of worthlessness, feelings of guilt, significant weight loss, recurrent thoughts of death (not just the fear of dying) and

fatigue or loss of energy nearly everyday (Kaplan, Sadock & Sadock, 2003). HIV positive women present with high levels of distress especially anxiety and depression in addition to the physical complaints associated with the disease. In the United States of America, the prevalence of anxiety and depression in individuals with a positive HIV diagnosis is much higher than in the general population (Visser, Mundell, deVilliers, Sikkema & Jeffery, 2005).

Anxiety and depression can result from a fear of discrimination, fear of opportunistic infections and a fear of death. Depression is often experienced at those times when an HIV positive individual feels most vulnerable. These vulnerable times include the initial adjustment to the HIV positive diagnosis, rejection following disclosure to family and friends and learning of a significant drop in one's CD4 count (Visser et al., 2005).

The experience of depression further complicates one's ability to effectively cope and manage the disease. This in turn results in non-adherence to medication and decreased levels of energy needed to focus on being healthy (Visser et al., 2005). Some studies also suggest that coping with a chronic illness such as HIV/AIDS by denial or avoidance is a predictor of non-adherence to medication. The impact of depression reduces the chances of many individuals living with the disease seeking assistance, in terms of information and treatment (Vyavaharkar et al., 2007; Visser et al., 2005).

Disclosure can reduce the debilitating effects that hiding a positive HIV diagnosis can induce, including anxiety and depression, associated with the initial shock of the diagnosis (Visser et al., 2005). Disclosure of a positive HIV diagnosis can also lower stress and lead to better psychological health (Deribe et al., 2008). Disclosure can encourage help-seeking behaviour in terms of accessing appropriate medical treatment, and garner social support to assist the individual to better deal and cope with the implications of living with HIV (Visser et al., 2005).

Disclosure of a positive HIV status can induce psychological distress if the response to the disclosure is negative, resulting in increased social isolation, rejection and stigmatization. This can also mean a poor prognosis for recovery. Against this complicated psychological landscape, it is inevitable that for many women (particularly in the initial stages of the disease) the psychological impact associated with the HIV diagnosis and the subsequent decision of whether or not to disclose, can far outweigh the physical affliction of being HIV positive. This is especially true against the backdrop of poverty and or the additional threat of violence (Visser et al., 2005).

In South Africa, for a woman living in a traditional black community, a positive HIV diagnosis can mean much more than being infected with the virus (Visser et al., 2005). The psychological effects the literature identifies as associated with a positive HIV diagnosis are:

- self-blame
- guilt
- shame
- shock/disbelief
- stigma
- anger
- denial
- anxiety/worry
- depression/sadness
- fear of death

In addition, chronic fatigue is a common symptom of HIV infection in all populations and is associated with physical and psychological morbidity. Studies have shown that women are more likely than men to report symptoms of fatigue. It is the most frequently reported and the worst symptom for HIV infected women (Bungener et al., 2000).

An individual's psychological response is also influenced by the emotional responses of significant others. Emotional responses from significant others (including family and friends) that have been associated with disclosure of a positive HIV diagnosis include stigma/discrimination, rejection, denial, shock/disbelief, blame, anger, rejection, embarrassment, worry, silence, hope and reassurance or comfort (Serovich et al., 1998).

These emotional responses from significant others following disclosure of a positive HIV diagnosis are the precursors as to whether support (be it emotional or instrumental) will be available. Thus, even after the disclosure target has been selected and disclosure has been undertaken, there remains a process whereby the social effects of the disclosure are felt. This is discussed in the next section.

### **2.9.7 Effects of social support on disclosure**

Although much emphasis has been placed on the relationship between social networks and the spread of HIV in Sub-Saharan Africa (Hutchinson, Mahlalela & Yukich, 2007), other aspects of social networks have not been explored. The role of social networks in reducing stigma and psychological distress and the uptake of HIV testing and the disclosing of HIV test results is often ignored.

Support from significant others has been known to buffer the impact of a wide variety of stressful life-events, including chronic illness. It has also been associated with improved psychological well-being and decreased depression and anxiety in homosexual men infected with HIV. It also influences the coping and recovering process from physical illness as well as increasing adherence to medical regimens (Vyavaharkar et al., 2007; Petrak et al., 2001).

Hough, Magnan, Templin & Gadelrab (2005) define social support as "the subjective feeling of belonging, of being accepted, loved, esteemed, valued and needed for oneself" (p.16). It is multi-faceted concept defined by the sources of support, the types of support (e.g. emotional and instrumental) and one's satisfaction with the support received. The

potential effectiveness and desirability of the different types of support are dependent largely on the individual's social context as well the type of support needed (Vyavaharkar et al., 2007).

Social support is fundamental for normal development, but is imperative for those who have to endure the complexities of a chronic illness, in that it has an effect on an individual's immune system and mortality risk when faced with a crisis or a serious illness (Lam et al., 2007; Kimberly & Serovich, 1996). It can enhance emotional well-being and becomes vital as a safeguard against HIV-related psychological distress and physical symptoms (Lam et al., 2007; Norman et al., 2007; Hough et al., 2005; Visser et al., 2005; Kalichman et al., 2003). For many individuals, the decision to disclose their positive HIV status must balance the need for social support specific to coping with HIV and AIDS against the potential loss of what could otherwise be supportive relationships (Kalichman et al., 2003).

Deribe et al., (2008) found that those individuals who experience high levels of social support tend to disclose their positive HIV diagnosis more often than those without support. Poor emotional well-being, including depression and HIV-related anxiety, has been attributed to lack of satisfaction with social support (Almeleh, 2006). One's satisfaction with the quality of support received following disclosure has the effect of lowering depressive symptoms brought on by HIV-related physical symptoms (Norman et al., 2007; Antelman et al., 2001).

### **2.9.8 Conclusion**

Disclosure of a positive HIV diagnosis is a complex and multi-dimensional process that transcends the individual's personal circumstances and moves into his or her social sphere. It involves a process of adjustment to the diagnosis, motivation of whether or not to disclose, whom to disclose to, as well as the consequences of making the disclosure. It would seem from this discussion that the process of disclosing a positive HIV diagnosis is unique to each individual and is informed to a large extent by his or her social context.

Disclosure of a positive HIV diagnosis is determined by an individual's personal beliefs, social and family environment and the prevailing community discourse around HIV/AIDS. The disclosure process is also influenced by the negotiation of fears around stigmatization from not only the immediate family, partner or husband, but also the community at large. The literature review sought to present some insight into the HIV and AIDS pandemic, with special focus on the vulnerability of women to HIV infection, as well as on the psychosocial effects of disclosure. The disclosure process involves more than the act of telling others about the positive HIV diagnosis, so as to access or garner support from significant others. It involves a process of adjusting to one's positive HIV diagnosis (which can take years), negotiating one's fears in anticipation of either positive or negative consequences of disclosure as well as the motivation to disclose.

This literature survey highlights the importance of disclosure with regards to HIV and AIDS. South Africa has one of the highest HIV infection rates in the world, with women being more vulnerable to HIV infection and disclosure remains a central dilemma for women who discover that they are HIV positive. Women's fears related to discrimination and rejection following disclosure of a positive HIV diagnosis to family or their partner are well documented in many studies. These findings place special focus on women and the manner in which they deal with their HIV infection and disclosure. The research methodology will be presented in the following chapter.

## **CHAPTER THREE**

### **THE INVESTIGATION**

#### **3.1 Introduction**

In this chapter, the research design and the method of the study will be set out. The motivation as well as the theoretical grounding for utilizing the qualitative approach to research will first be discussed.

#### **3.2 The Qualitative approach to research**

Qualitative research design is used to describe life experiences and to give meaning to them (Burns & Grove, 2001). Qualitative research design allows for a richness of data to be generated, and also allows the researcher to ask questions that would not be possible if research were limited only to quantitative methods, as it can embrace ambiguity and complexity in its results. The choice of a qualitative research design was informed by the researcher's understanding of the problem and the purpose for the study.

An exploratory approach to research is undertaken when “a new area or topic is being investigated with the aim of shedding light on ways in which a phenomenon is manifested and on underlying processes” (Polit, Beck & Hungler, 2001, p. 19). The subject of the HIV and AIDS pandemic has been widely researched however; an investigative or exploratory approach is indicated in this case, as there is a dearth of literature around the psychosocial effects of disclosing a positive HIV diagnosis in South Africa, more especially in the KwaZulu-Natal province, which records the highest prevalence of HIV infections in the country.

#### **3.3 RESEARCH DESIGN**

Burns & Grove (2001) define a research design as the “blueprint for conducting the study, as well as the end-result of a series of decisions made by the researcher concerning how the study will be implemented” (p. 223). This process includes the aim of the study,

the research question, research methodology, sample group, data gathering and data analysis.

### **3.3.1 Aim of the study**

The aim of this investigation is to explore, on a preliminary basis, the psychosocial effects on a sample of women of having disclosed their positive HIV diagnosis.

### **3.3.2 Research Questions**

What are the psychological effects of disclosing a positive HIV diagnosis?

What are the social effects of disclosing a positive HIV diagnosis?

### **3.3.3 Objectives of the study**

1. To explore the psychological effects on a sample of women following disclosure of a positive HIV diagnosis
2. To explore the social effects on a sample of women following disclosure of a positive HIV diagnosis

### **3.3.4 Procedure**

Permission to conduct the study needs to be granted and obtained from the appropriate Faculty Ethics Committee of the University of Limpopo (Medunsa campus) for ethical clearance. Permission will also be sought and obtained from the manager who runs the Hillcrest AIDS Centre Trust where the study is to be conducted.

Hillcrest is a suburb situated on the outskirts of Durban and has a population of about 28 000 people. It is chosen because it is easily accessible. Near Hillcrest lies a peri-urban community known as the Valley of a Thousand Hills that according to some studies is also the seat of the HIV/AIDS epidemic in KZN. The results of a survey done by the

Medical Research Council in Durban (2006) on the prevalence of HIV infection among women in Durban shows that the incidence of HIV infection in Durban and surrounding areas is high with 5 out of every 100 being infected with HIV every year. The situation in the Valley is far worse. Recent studies have shown that in some parts of the Valley up to 66% of women are HIV positive (Kroonin, 2008).

The Hillcrest AIDS Centre Trust (HACT) was founded in 1991 in response to the growing epidemic. It is a non-government organization that focuses on education (around HIV and AIDS), face-to-face counseling for people infected with HIV, as well as their families, income-generated activities and home based care. Most of the women who attend the various programmes offered at HACT come from the Valley.

The Hillcrest AIDS Centre Trust is the closest appropriate research centre in terms of proximity to the researcher and it is accessible to persons who fit the criteria and who might be willing to participate in the study. The researcher will make a request at the centre that announcements concerning the research be made. Participants in the study will be requested to volunteer to ensure that they are not unduly pressured into participating in the study, and will be made aware that their privacy is respected (even if they have disclosed their status). This forms part of confidentiality considerations. Subsequent to information regarding the study being given, those who are interested in participating in the study will let the counselor at the centre know, upon which appointments with the participants will be made at the participants' convenience.

Informed consent will be obtained with the use of a standard form and will be orally explained in accordance with the information contained on the form. This is to ensure that any confusion that could result from language differences and illiteracy is eliminated. Written consent will be obtained from the participants and only participants who complete the consent form will be included in the study. Anonymity of the participants will be protected, as no indication of names or addresses will be disclosed on the forms. All questions from the participants regarding the aim and objectives of the research will be dealt with honestly and openly. Each interview that is to be conducted by the

researcher will be conducted in a quiet and private space at the centre. It is anticipated that each interview will last anywhere from 30- 90 minutes, depending on individual circumstances. As the researcher is the data-collecting instrument, the researcher's continuing training as a Clinical Psychologist, qualifications and experience are also important, as they make for an ideal interviewer and thereby establish confidence in the data. This aspect is also referred to as researcher credibility (Polit et al., 2001). The three independent clinicians involved in the data analysis will be selected on similar grounds, as they will also be continuing their training as Clinical Psychologists.

### **3.3.5 Sample**

Sampling refers to the process of selecting a portion of the population to represent the entire population (Polit & Hungler, 1999). A convenience sampling approach will be used in this study. This is an example of non-probability sampling, used when it is necessary to obtain a sample from an unknown population (Gerrish & Lacey, 2006). In convenience sampling, subjects are entered into the study until the desired sample size is reached and because they happened to be in the right place at the right time (Burns & Groves, 2001).

Participants in the study will also be requested to identify and refer other people who meet the study criteria. This sampling approach is another form of convenience sampling, also known as snowball sampling (Polit & Hungler, 1999). The sample will be further selected based on the following inclusion and exclusion criteria:

#### ***3.3.5.1 Inclusion Criteria***

- Female – this criterion is included, as the study will focus specifically on women.
- Older than 18 – this criterion serves to ensure that only adults are included in the study
- Positive HIV status – this is one of the key inclusion criteria
- Disclosed their positive HIV status – in accordance with the definition of

- disclosure used in this study, which is that they have voluntarily disclosed to sexual partners, intimate or immediate family, extended family and or friends
- Are attending the Hillcrest AIDS Centre Trust – this is the centre which will be asked for permission to conduct the study.

### **3.3.5.2 Exclusion Criteria**

- The main exclusion criterion is non-disclosure. Other exclusion criteria include gender and age

### **3.3.5.3 Sample size**

Although the HIV infected population in South Africa is large, it is not possible to access all members of this population. Instead, the population, which is practically available for this study, is the attendees at the Hillcrest AIDS Centre Trust. In order to attend this centre, the individual must have disclosed their status to at least one other person.

The exclusion criteria of age, gender and non-disclosure as well as the voluntary nature of the study are factors that could effect participation. In addition, the fact that the various programmes at the Centre are offered only on specific days of the week in an attempt to combat rising transport costs, will also affect the participants' availability. Therefore, the population from which the sample is drawn is that of female attendees at the Hillcrest AIDS Centre Trust, all of whom have disclosed their positive HIV status to at least one other person.

Due to the confidential nature of the topic, it is not possible for the researcher to have truly random sampling, defined by Burns & Grove (2001) as a selection process in which each individual in the population has an equal chance of being selected, as random sampling increases the extent to which the sample is representative of the target population. In this study, it will not be possible for the researcher to approach the participants, as the participants will have to volunteer to be a part of the study, and this

therefore limits true randomness. Therefore, members of the population will volunteer themselves for inclusion in the sample.

In qualitative research, the sample size is determined by the quality of data collected (Polit & Hungler, 1999). In this study, the sample size will be determined by the richness of the data generated by the interviews, and sampling will continue until a point of data saturation has been reached. Data saturation is defined as that point at which themes begin to repeat themselves within the interviews, without offering anything new. It is the point at which no new information is emerging from the interviews (Polit & Hungler, 1999).

### **3.3.6 Data Gathering**

Data collection is the precise and systematic gathering of information relevant to the research questions or purpose of a study (Burns & Grove, 2001). Because the women's process of disclosing their positive HIV diagnosis and the psychosocial effects subsequent to their disclosure is of primary interest, questions will focus on whom the individual disclosed to following discovery of the HIV diagnosis as well as the motivation for the disclosure.

The most effective way of securing the data for the study is to conduct focused or semi-structured interviews with the participants. Semi-structured interviews are used when the researcher has a list of topics that must be covered in the interview (Polit et al., 2001). Stimulus questions will include:

- “Who did you disclose to first, after you found out that you had the virus?”
- “Why did you choose that person first?”
- “How did you tell this person?”
- “How did this person react/respond to what you were telling them?”

Psychological themes around the internal reactions following disclosure, such as feelings of depression, rejection and anxiety, will be explored and overt behaviours during the interview process observed. Social themes around the sources and types of support, as well as satisfaction with support received, as formulated from the literature review, will also be explored during the course of the interviews. Interviews will be audio-recorded and conducted in the participants' language of preference. This will be done to minimize bias, especially concerning those participants who meet the inclusion criteria but speak the language indigenous to the province of KZN, which is isiZulu.

In qualitative studies, the researcher is the data-collecting instrument (Polit et al., 2001). The researcher in the interviewing process will endeavor to establish trust and rapport with the participants by using person-centered interviewing skills developed by Carl Rogers. This form of interviewing is essential in providing the individual with "an optimal climate under which to set out his or her difficulties, without being restricted in a significant way. It creates an environment in which he or she can feel understood, accepted and respected" (Vorster, 2003, p. 101).

### **3.3.7 Data Analysis**

Data analysis is the systematic organization and synthesis of research data; conducted to reduce, organize and give meaning to data (Burns & Grove, 2001; Polit & Hungler, 1999). In this study, content data analysis will be conducted. The central idea in content analysis is that the many words of the text are classified into fewer content categories. These individual words, word combinations or themes must be defined to enable the researcher to develop rules for identifying and recording them (Burns & Grove, 2001).

This involves a systematic means of measuring the frequency and intensity of the occurrence of words, phrases or sentences. Words, phrases or other units of the text are presumed to have similar meanings. However, reliability and validity problems arise when categories or word meanings become ambiguous (Weber, 1990).

What this is referring to is that variables in content analysis are valid to the extent that they measure the construct the researcher intends them to measure. In accordance with the steps of content analysis, as outlined by Weber (1990), the following steps are an integral part of content analysis and will be utilized in this study:

- **Defining the recording units** by ensuring that long, complex sentences are broken down into shorter thematic units
- **Defining the categories** through deciding whether categories should be narrow or broad; included in this step, is the decision whether the categories should be mutually exclusive in that words chosen to define the phenomenon of interest clearly belong in that category. The researcher, with the help of three independent clinicians, will code the transcripts for content, based on the interview dialogue, with sections pertaining to disclosure and the psychosocial effects following disclosure being isolated in the text.

The use of two or more trained researchers to analyze and interpret a set of data is referred to as investigator triangulation. Through collaboration with other trained researchers, the possibility of a biased or a one-sided interpretation of the data is reduced. Investigator triangulation ensures that any bias on the part of the researcher is probed, the credibility of the themes identified enhanced and the basis of the interpretation clarified (Polit & Hungler, 1999). Investigator triangulation assumes that the various parties involved are familiar with the language used in the transcripts, thus ensuring that there is mutual agreement with words placed in the same categories, based on the assumption that the words have similar meanings or connotations.

- **Testing coding on a sample of text**, which often reveals whether revisions should be made regarding the classification of categories.
- **Assessment and re-assessment of accuracy or reliability-** investigator triangulation regulates this.

- **Revision of coding rules and coding of all relevant text**, which is based on aforementioned step.

The various parties will identify and establish the categories, themes or recurring processes separately using content analysis. The themes in the transcripts as well as from the literature review will be utilized as a guide. Thus, prior knowledge that the literature has associated depression with HIV disclosure may identify depression as a possible theme to look for in the transcripts.

### **3.3.8 Credibility and Dependability of Qualitative research**

In qualitative research, validity and reliability are measured through the evaluation of the credibility and dependability respectively of the data. Credibility refers to confidence in the truth of the data and dependability refers to the stability of the data over time and over conditions (Polit & Hungler, 1999).

Transferability refers to the extent to which the findings from the data can be transferred to other settings or groups. This rests with the researcher to provide sufficient information so a conclusion can be reached about whether the findings from the data are transferable or can be generalized (Polit et al., 2001). The final interpretation of the data lies with the researcher, and will be conducted based on the researcher's observation during the interviewing process as well as an understanding of the themes generated through the triangulation process.

In a study, bias has the potential to affect the meaning of the research findings. Bias can result from a number of factors in research. These include the researcher, the measurement tools, the individual subjects, the sample, the data and the statistics (Burns & Grove, 2001). In this study, bias will be minimized through the use of investigator triangulation in interpreting the data as well as the transcribing of the data from the tape recordings verbatim. The researcher is predominantly isiXhosa speaking and therefore to maintain data integrity and to minimize researcher bias, the transcripts will be translated

from isiZulu into English by an experienced translator whose mother tongue is isiZulu. The transcripts will then be checked for accuracy by both the researcher and the translator.

The researcher is not external to the research, but forms an integral part of it. It is not possible to fully eliminate bias. However, the researcher's acknowledgement of subjectivity during the research process leads to an awareness of possible bias, which allows the researcher to attempt to minimize and account for it, while at the same time realizing that within this type of research, bias will always remain a factor.

## **3.4 METHOD**

### **3.4.1 Research Procedure**

The research procedure as set out by the research design was followed. The interviews were conducted between July and August 2008 at the Hillcrest AIDS Centre Trust, following a brief description of the aim and objectives of the study. The interviews were audio- recorded, transcribed and translated in accordance with the research design.

### **3.4.2 Research Sample**

Sampling was conducted as set out in the research design.

### **3.4.3 Data Gathering**

Data was gathered as proposed in the research design.

### **3.4.4 Data Analysis**

Data analysis was conducted as set out in the research design. The results and discussion are presented in the next chapter.

## **CHAPTER FOUR**

### **RESULTS AND DISCUSSION**

#### **4.1 Introduction**

In this chapter, the results and discussion will be presented. The chapter will end with an overall integration, discussion and conclusion.

#### **4.2 RESEARCH RESULTS**

##### **4.2.1 Presentation of results**

The results are presented in sections 4.2.4 through to 4.2.8. For each of the five participants interviewed, a table is presented along with some brief demographic data. Each table contains a list of themes identified by the independent clinicians. Following the table, an integration of the themes (in order of prominence) is presented. In other words those themes which were identified by all three clinicians, are integrated first, then the themes identified by only two of the clinicians, and lastly the themes which were identified by only one clinician. In some cases, brief extracts from the transcripts have been included in order to illustrate the themes identified.

In order to facilitate ease of presentation, in the integrations that follow the tables, the themes have been underlined. Thus, each theme can be identified easily while reading the integration.

Once each of the participant interview transcripts has been presented in this manner, the chapter moves on to an overall discussion and integration of the common themes identified as spanning all five of the interviews.

## **4.2.2 Independent Clinicians**

As specified in the previous chapter (under section 3.3.7) three independent clinicians evaluated the interview transcripts. All three of the clinicians were either Clinical Psychologists or Clinical Psychologists in training. Each of the clinicians was emailed the transcripts and then responded with a list of themes that they identified for each participant. The clinicians did not integrate the themes across participants, but rather focused on themes emerging from the individual interviews. The themes identified by the clinicians covered both the psychological and social aspects of disclosure of a positive HIV diagnosis. The tables below integrate the clinicians' findings for each participant.

## **4.2.3 Ethical considerations**

The data set consisted of interviews with five participants. The participants specifically requested that their transcripts not be included in any published data. Therefore, in respect of their wishes the full transcripts are not included in this research report. The transcripts are however available on request (in respect of bona fide research).

## **4.2.4 Participant 1**

Participant 1 is in her late thirties. She was diagnosed HIV positive in 2002. As part of the PMTCT programme, she had been tested for HIV at her local clinic. However, she had delivered her baby prior to receiving her positive HIV blood test results. She is widowed, having lost her husband to AIDS.

**Table 4.2.4.1 Prominent themes for participant 1**

<b>THEMES</b>	<b>CLINICIAN 1</b>	<b>CLINICIAN 2</b>	<b>CLINICIAN 3</b>
<b>Shock and disbelief</b>	X	X	X
<b>Immediate disclosure</b>	X		
<b>Disclosure to a family member</b>	X		X
<b>Fear of stigma/discrimination</b>	X	X	X
<b>Lack of partner support following disclosure</b>	X		X
<b>Hopelessness</b>		X	X
<b>Self-blame/Guilt</b>			X
<b>Acceptance</b>	X		
<b>Satisfaction with support following disclosure</b>	X	X	X
<b>Experience of stigma/discrimination following disclosure</b>	X	X	X
<b>Concern for children’s well-being</b>	X		X
<b>Anger</b>	X	X	X
<b>Depression</b>	X	X	X

**4.2.4.1.1 Integration**

a) Themes identified by all *three* independent clinicians

The participant’s responses following discovery of her positive HIV diagnosis, were shock and disbelief, feelings of anger (especially towards the husband), depression and fear of stigma/discrimination following her positive HIV diagnosis.

Following disclosure of her HIV positive diagnosis, the participant experienced satisfaction with the support received, especially from her mother. However, the participant also had experiences of stigma/discrimination following disclosure of her HIV positive status from both her family members and her neighbours.

Thus, the most prominent themes for this participant were:

- Shock and disbelief

- Anger
- Depression
- Fear of stigma/discrimination
- Satisfaction with the support received
- Experiences of stigma/discrimination following disclosure

b) Themes identified by two independent clinicians

Her initial disclosure was to a family member, namely her mother, followed by her husband. Clinician 1 further identified that immediate disclosure took place, as she disclosed to both her mother and her husband on the same day that she discovered her HIV positive status. There was a lack of partner support following her disclosure of a positive HIV diagnosis. She was concerned for the children's well-being following the death of her husband, as she had been financially dependent on him, which exacerbated her feelings of hopelessness.

c) Themes identified by only one clinician

Clinician 1 identified feelings of self-blame, as she was aware of her husband's infidelity, but she assumed that he was using a condom. A sense of acceptance of her positive HIV status was identified by clinician 3.

#### **4.2.5 Participant 2**

Participant 2 is in her early twenties. She was diagnosed HIV positive in 2001, after her one-month old baby was diagnosed HIV positive. Following this diagnosis, participant only disclosed her HIV status in 2007, after her second child fell ill due to AIDS-related complications and due to participant's own deteriorating health status.

**Table 4.2.5.1 Prominent themes for participant 2**

THEME	CLINICIAN 1	CLINICIAN 2	CLINICIAN 3
Shock and disbelief	X	X	X
Did not disclose for a long time	X		X
Disclosure as a result of deteriorating health	X		X
Disclosure to a family member	X		X
Fear of stigma/discrimination	X		X
Lack of partner support following disclosure	X		X
Hopelessness	X	X	X
Self-blame/Guilt	X	X	X
Acceptance	X		X
Satisfaction with support following disclosure	X		X
Hope	X		X
Anger	X	X	X
Depression	X		X
Denial		X	X
Stress		X	X
Shame			X

#### 4.2.5.1.1 Integration

##### a) Themes identified by all *three* independent clinicians

Participant’s immediate responses following discovery of her positive HIV diagnosis, were shock and disbelief. She describes her reaction as being that, “I didn’t believe it ... because I didn’t see myself as someone who could get this...”

She then experienced a great deal of self-blame, which led to hopelessness and anger, especially towards herself. She described the feeling as, “I had brought shame onto myself ... I thought about the life I used to live ... that maybe I turned my life around a little too late...”

Thus, the most prominent themes for participant 2 were:

- Shock and disbelief
- Self blame
- Hopelessness
- Anger

b) Themes identified by *two* independent clinicians

Clinicians 1 and 3 identified that the participant did not disclose for a long time following her positive HIV diagnosis. This can be attributed to the participant's above-mentioned responses. Denial, fear of stigma/discrimination, depression and stress following her positive HIV diagnosis could also be contributing factors to the participant's non-disclosure of her positive HIV status. Participant eventually disclosed as a result of deteriorating health. Her initial disclosure was to a family member, namely her younger sister. She experienced satisfaction with the support following disclosure that she received from her sister. However, there was a lack of partner support following disclosure of her positive HIV status. The participant's subsequent acceptance of her positive HIV status as well as hope, identified by clinicians 1 and 3, are a result of the support that she received from her sister following disclosure of her positive HIV status.

c) Themes identified by only *one* independent clinician

Clinician 3 identified shame as one of the factors that could have also influenced the participant's non-disclosure following her positive HIV diagnosis.

#### **4.2.6 Participant 3**

Participant 3 is in her late thirties. She is a single parent with two children. She was diagnosed HIV positive in 1997, following an STI infection and TB diagnosis.

**Table 4.2.6.1 Prominent themes for participant 3**

<b>THEMES</b>	<b>CLINICIAN 1</b>	<b>CLINICIAN 2</b>	<b>CLINICIAN 3</b>
<b>Shock and Disbelief</b>	X	X	X
<b>Did not disclose for a long time</b>	X		X
<b>Disclosure as a result of deteriorating health</b>	X		X
<b>Disclosure to a family member</b>	X		X
<b>Fear of stigma/discrimination</b>	X		X
<b>Hopelessness</b>			X
<b>Satisfaction with support following disclosure</b>	X		
<b>Experience of stigma/discrimination</b>		X	X
<b>Hope</b>	X		X
<b>Concern for children’s well-being</b>	X		X
<b>Anger</b>	X		X
<b>Depression</b>	X	X	X
<b>Fear of death</b>		X	X
<b>Denial</b>		X	X
<b>Rejection</b>		X	X
<b>Isolation following disclosure</b>		X	X

**4.2.6.1.1 Integration**

a) Themes identified by all *three* independent clinicians

Participant’s immediate response following discovery of her positive HIV diagnosis, were shock and disbelief. She says, “I didn’t want to believe what they were telling me... nothing in my head was telling me that it was this... I didn’t even cry... I just told myself there is nothing like this...”

The participant then lapsed into what seems to be a severe depression following her admission to hospital for TB.

Thus, the most prominent themes for participant 3 were:

- Shock and disbelief

- Depression

b) Themes identified by two independent clinicians

Clinicians 1 and 3 identified that the participant did not disclose for a long time following her positive HIV diagnosis. Contributing factors could include her fear of stigma/discrimination (“The problem was now I had to tell where... at home... I had this picture in my head and it told me if they find out at home ... they won’t accept me... I’ll have my own plate and my own cup...”). Her lack of disclosure could also be related to her denial. Participant disclosed as a result of deteriorating health, concern for her children’s well-being and a fear of death. Initial disclosure was to a family member, namely a younger sister. Following her disclosure of her positive HIV status, participant’s experience of stigma/discrimination from family members resulted in feelings of isolation and rejection following the disclosure. Participant’s feelings of anger could be attributed to the perceived lack of support from her family. However, a support group for people living with HIV and AIDS (PLWHA), at the hospital gave the participant hope.

c) Themes identified by only one independent clinician

Lack of perceived support from family members following disclosure could have intensified feelings of hopelessness identified by clinician 3. However, satisfaction with support received following disclosure, identified by clinician 1, was attributed to the support group at the hospital.

#### **4.2.7 Participant 4**

Participant 4 is a single parent with two children. She is in her forties and was diagnosed HIV positive in 2002.

**Table 4.2.7.1 Prominent themes for participant 4**

<b>THEMES</b>	<b>CLINICIAN 1</b>	<b>CLINICIAN 2</b>	<b>CLINICIAN 3</b>
<b>Suspected positive HIV status before diagnosis</b>	X		
<b>Disclosure to a friend</b>	X		X
<b>Fear of stigma/discrimination</b>	X		X
<b>Acceptance</b>	X		X
<b>Satisfaction with support following disclosure</b>	X		X
<b>Experience of stigma/discrimination</b>	X	X	X
<b>Hope</b>	X		X
<b>Concern for children’s well being</b>	X		X
<b>Anger</b>	X	X	X
<b>Fear of death</b>		X	X
<b>Isolation following disclosure</b>		X	X

**4.2.7.1.1 Integration**

a) Themes identified by all *three* independent clinicians

Participant’s feelings of anger were attributed to experiences of stigma/discrimination, from some members of her community who suspected that she was HIV positive because of her apparent weight-loss. She dramatically describes one experience: “I remember a day when I was coming back from church and this woman said to me: ‘Haven’t people told you that you shouldn’t be seen walking in the street now.’ I asked her why not and she said; ‘You are a skeleton now...’ I got angry, I was angry because I have never forgotten until today...”

Thus, the most prominent themes for participant 4 were:

- Anger
- Experiences of stigma/discrimination

b) Themes identified by two independent clinicians

Participant's responses following discovery of her positive HIV diagnosis, were concern for her children's well-being, fear of stigma/discrimination and fear of death. Clinicians 1 and 3 identified that initial disclosure was to a friend. Following disclosure of her positive HIV status, participant experienced satisfaction with support following her disclosure, from her friend. Her feelings of acceptance of her positive HIV status, and hope could be ascribed to the support she received from her friend. However, she did experience feelings of isolation following disclosure.

c) Themes identified by only one independent clinician

Participant 4 had suspected her positive HIV status before the diagnosis, due to ill-health, as identified by clinician 1.

#### 4.2.8 Participant 5

Participant 5 is a single parent with two children. She is in her twenties and was diagnosed HIV positive in March 2008. She had nursed both her mother and her brother before they both succumbed to AIDS and died. At the time of the interview, she had been living with HIV for about 5 months.

**Table 4.2.8.1 Prominent themes for participant 5**

THEME	CLINICIAN 1	CLINICIAN 2	CLINICIAN 3
<b>Shock and disbelief</b>	X		X
<b>Fear of stigma/discrimination</b>	X	X	X
<b>Disclosure to partner</b>	X		X
<b>Lack of partner support following disclosure</b>	X		X
<b>Acceptance</b>	X		X
<b>Anger</b>	X	X	X
<b>Blame</b>		X	X

#### 4.2.8.1.1 Integration

a) Themes identified by all *three* independent clinicians

Participant's responses following discovery of her positive HIV diagnosis, were anger, especially towards the partner, and fear of stigma/discrimination. She says; "It is difficult to tell someone who doesn't have it [HIV] because it means now that you are just like an animal ... another person is disgusted by you..."

Thus, the most prominent themes identified for participant 5 were:

- Anger
- Fear of stigma/discrimination

b) Themes identified by *two* independent clinicians

Participant also responded to her positive HIV diagnosis with shock and disbelief. She also experienced feelings of blame towards the partner for infecting her. Initial disclosure was to the partner and there was a lack of partner support following disclosure.

There is now a sense of acceptance of her positive HIV status.

c) Themes identified by only one independent clinician

No themes were identified by only one clinician.

#### 4.2.9 INTEGRATION AND DISCUSSION OF THEMES

In total, the clinicians identified 26 themes in the five participant interviews. Some of these themes were identified in the transcripts of all the participants, while some of the themes were unique to a particular participant. In the table below, all of the themes identified are listed. The table also identifies whether a particular theme was present in the transcript of a participant, as well as how many of the clinicians (1, 2 or 3) identified the theme for the participant.

**Table 4.2.9.1 Prominent themes across all five participants**

<b>Themes</b>	<b>P.1</b>	<b>P.2</b>	<b>P.3</b>	<b>P.4</b>	<b>P.5</b>
Shock and disbelief	3	3	3		2
Immediate disclosure	1				
Disclosure to a family member	2	2	2		
Fear of stigma/ discrimination	3	2	2	2	3
Lack of partner support following disclosure	2	2			2
Hopelessness	2	3	1		
Self-blame/Guilt	1	3			
Satisfaction with support received following disclosure	3	2	1	2	
Experience of stigma/discrimination	3		2	3	
Concern for children's well being	2		2	2	
Acceptance	1	2		2	2
Anger	3	3	2	3	3
Depression	3	2	3		
Did not disclose for a long time		2	2		
Disclosure as a result of deteriorating health		2	2		
Hope		2	2	2	
Denial		2	2		
Stress		2			
Shame		1			
Fear of death			2	2	
Rejection			2		

Isolation following disclosure			2	2	
Suspected positive HIV status before diagnosis				1	
Disclosure to a friend				2	
Disclosure to a partner					2
Blame					2

#### **4.2.9.1.1 Themes identified in all five transcripts:**

Only two themes were identified in all five of the transcripts. These were a fear of stigma/discrimination, and a feeling of anger.

The fear of stigma/discrimination was very prominent in the transcripts as in two cases three clinicians identified it, while in the remaining three transcripts two of the clinicians identified the fear of stigma/discrimination as a major theme. Therefore, we can conclude that a fear of stigma/discrimination played a large role in the decision of whether or not to disclose a positive HIV status. This is especially interesting in that the actual experience of stigma/discrimination was only highlighted in three of the five transcripts. Thus, a fear of stigma/discrimination does not seem to be necessarily tied to the actual experience of stigma/discrimination.

Anger was the most commonly identified theme in the transcripts (only one clinician did not identify anger as a theme for participant 3, aside from this, it was universally identified by all the clinicians across all five transcripts). Thus, anger seems to be a key reaction to the positive HIV diagnosis. It would therefore make sense that this same anger plays a role in the disclosure process.

These themes were common to the transcripts, and as such, they are therefore indicative of commonalities across individuals. Thus, they indicate areas of agreement between the transcripts that can be seen as a starting point for the discussion of the research questions, which follows.

#### **4.2.9.1.2 Themes identified in four of the five transcripts:**

Shock and disbelief was identified as a strong theme in all but one of the transcripts. (The exception is participant 4, who suspected her positive HIV status prior to diagnosis due to her already deteriorating health). Many of the participants were unable to believe the diagnosis they were given. This relates to the disclosure process, as it is difficult for a person to disclose if they themselves do not believe the diagnosis. This was made clear by participant 3, who stated that although she had been told that she was HIV positive, she believed that a mistake had been made and that the vials containing her blood had been switched with those of an HIV positive individual.

The word acceptance appeared frequently in the transcripts, and thus emerged as a prominent theme. To the interviewer, the acceptance seemed to signify a type of resignation, or inevitability about the positive HIV diagnosis rather than a true acceptance of the illness.

Surprisingly, four of the five participants indicated that they were satisfied with support they received following disclosure. This is surprising given the extreme fear of stigma that was identified in all five transcripts.

#### **4.2.9.1.3 Themes identified in three of the five transcripts:**

Disclosure to a family member was identified in three of the five transcripts. Participant 1 disclosed to her mother, while participant 2 and 3 disclosed to their younger sisters. The literature suggests that female family members are likely to be perceived as more supportive and compassionate than male family members prior to the disclosure of a positive HIV diagnosis.

Three of the five participants experienced a lack of partner support following disclosure of a positive HIV diagnosis. Responses to the disclosure ranged from silence to anger and accusations of infidelity, as in the case of participant 5. This is in keeping with some studies in the literature which cite that disclosure of a positive HIV diagnosis may result in a lack of partner support following disclosure, as well accusations of infidelity and in some extreme cases physical threats of violence.

Hopelessness, one of the recognized features of severe depression was identified in participants 1, 2 and 3, who are interestingly also the same three participants who experienced depression following diagnosis of a positive HIV diagnosis. In two cases, three clinicians identified depression as a prominent theme, and in the remaining case, two clinicians identified depression. Many studies documenting HIV/AIDS and disclosure, have suggested that depression may result as a response to the initial adjustment to a positive HIV diagnosis or from the rejection by family or friends following disclosure, to name a few. These studies also suggest that the experience of depression can contribute in hindering the disclosure process of a positive HIV status.

Earlier in this discussion, it was concluded that fear of stigma/discrimination plays a key role in the decision of whether an individual discloses their positive HIV status or not. All five of the participants presented with a collective and prominent fear of stigma/discrimination following their positive HIV diagnosis. Literature attributes this to the pre-existing, prejudicial social discourse and somewhat entrenched misconceptions around HIV/AIDS inherent in some communities and households. Consequently, three out of five participants had experiences of stigma/discrimination, from either family members or members of their community following disclosure of a positive HIV diagnosis.

Concern for children's well being was identified in three of the five participants. It has been suggested that concern for the well being of children in women who discover their positive HIV status, influences and at times accelerates the need to disclose, in accessing

much needed instrumental support, especially for the children in the event of illness or death.

Hope was identified for three of the five participants, stemming from satisfaction with support received following disclosure from family members (participant 2) and friends (participant 4). Participant 3 describes how a hospital support group for PLWHA gave her hope, following her perceived lack of support from members of her family after she disclosed her positive HIV status. This suggests that support following disclosure of a positive HIV diagnosis is not exclusive, nor is it restricted to an individual's family circle.

#### **4.2.9.1.4 Themes identified in two of the five transcripts:**

Self Blame/Guilt was identified for two of the five participants. Participant 1 expresses that she had known of her husband's infidelity, while participant 2 blamed her lifestyle choices for her HIV infection. The literature suggests that the highest prevalence of HIV infection is amongst committed or stable relationships, especially because women perceive these relationships to be "HIV-risk" free.

In two cases, disclosure did not take place for a long time following diagnosis of a positive HIV diagnosis. Non-disclosure of a positive HIV diagnosis, has been attributed to factors such as fear of stigma/discrimination, self-adjustment to the positive HIV diagnosis, fear of being labeled HIV positive and fear of rejection and being a burden to family members, to mention but a few.

The two participants who did not disclose for a long time following a positive HIV diagnosis, also disclosed as a result of deteriorating health. Participant 3 expresses that she did not believe that she was HIV positive, as she was a size 38, even after her admission to hospital for TB. Some studies have suggested that in some communities in South Africa, extreme weight loss is associated with AIDS illness. This impacts on disclosure of HIV infection, as it is avoided if an individual believes that they can still hide the illness. As the disease progresses, frequent hospitalizations may result, rendering

the afflicted individual incapable of hiding the illness. Thus suggesting that disease progression or deteriorating health due to HIV infection may influence the decision of whether disclosure takes place or not.

Interestingly enough, denial was identified as a theme for the two participants who did not disclose for a long time following a positive HIV diagnosis, suggesting that the psychological adjustment to the initial HIV diagnosis is an ongoing process that pervades every aspect of the individual in not only the disclosure process but also in managing the disease.

Fear of death was identified in two of the five participants. The literature cites a fear of death as one of the psychological responses inherent following discovery of a positive HIV diagnosis.

Isolation following disclosure was identified in two of the five participants. This may result if support that is anticipated following disclosure is not forthcoming. In the case of participant 3, dissatisfaction with support received from family members following disclosure resulted in feelings of isolation.

#### **4.2.9.1.5 Themes identified in only one of the five transcripts:**

Immediate disclosure following a positive HIV diagnosis was identified in participant 1 by only one clinician.

Stress was identified by two clinicians and shame was identified by only one clinician in participant 2, as responses to her positive HIV diagnosis.

Rejection following disclosure of a positive HIV diagnosis to family members was identified in participant 3, by two clinicians.

Participant 4, suspected her HIV status before diagnosis, as identified by only one clinician. She is thus the only participant who did not experience shock and disbelief following her positive HIV diagnosis.

Participant 4 disclosed to a friend as identified by two clinicians.

Participant 5 disclosed to her partner as identified by two clinicians. Two clinicians also identified blame (towards the partner for infecting her with HIV), in participant 5.

The above-mentioned themes were only found in single transcripts and were not common to more than one participant. Thus, they are not themes which can be seen as transcending the individual, but rather should be viewed as unique to that individual's specific response.

#### **4.2.9.1.6 Discussion**

The sections above have served to highlight in detail the various themes that were identified in the transcripts. It now remains to integrate these themes into a coherent discussion, and to see how they apply to the initial research questions, which are:

What are the psychological effects of disclosing a positive HIV diagnosis?

What are the social effects of disclosing a positive HIV diagnosis?

In the discussion below, each of these research questions is addressed separately. From the previous presentation of the various themes, the themes that were most prominent are highlighted in order to answer the research questions.

##### **4.2.9.1.6.1 Psychological effects of disclosure of a positive HIV diagnosis as identified by the three independent clinicians across five participant transcripts**

Participants' psychological responses to their positive HIV diagnosis play a pivotal role in the disclosure process and vary according to each participant's social context and

unique response to the diagnosis. However, in this particular study there were psychological responses to the positive HIV diagnosis that influenced the disclosure process, which were common to all the participants interviewed.

**Anger**, identified previously, was the single most prominent emotive response in the transcripts. Participants expressed anger at their positive HIV diagnosis, at the responses of others following disclosure of their diagnosis and at themselves. The anger did not necessarily lessen as a result of disclosure. Thus, disclosure did not serve to decrease the anger about the diagnosis and in some cases increased anger directed at others perceived as non-supporting. Even during the interview process, the participants continued to express anger at the situation.

**Fear of stigma/discrimination** was also a major psychological response following a positive HIV diagnosis, identified in the transcripts. This fear not only affected the participants' self-image or self-view following positive HIV diagnosis, but was also to a degree a barometer for assessing whether to avoid or go through the disclosure process, especially in the choice of disclosure target. Fear of stigma/discrimination was also projected onto perceptions (preconceived by the participants) of anticipated support should disclosure take place. In that for some participants, negative expectations of a lack of support (whether real or imagined) were induced by fear of stigma/discrimination prior to disclosure.

**Shock and disbelief** was recorded as the initial response to the diagnosis. This could be related to the fact that only one of the five participants disclosed their status immediately. It seems that the majority of the participants had to adjust psychologically to the diagnosis themselves before it was possible for them to disclose to others. Some studies have documented the beneficial effects of disclosing a positive HIV diagnosis, in for one reducing anxiety associated with discovering one's positive HIV status. However, for the participants, shock and disbelief at the positive HIV diagnosis did not necessarily lessen

as a result of the disclosure. For the majority of the participants, it remains an underlying but strong emotion.

**Acceptance** emerged as a prominent theme in the transcripts. However, it seemed to signify a type of resignation about the positive HIV diagnosis rather than a true reflection of acceptance of the illness. It can be hypothesized that the anger expressed by all the participants towards their positive HIV diagnosis can be associated with this false sense of acceptance.

It is important to note that the above-mentioned psychological responses to both the discovery of a positive HIV diagnosis and subsequent disclosure are highlighted due to their universal prominence across all five of the participants. Other psychological responses expressed at the initial positive HIV diagnosis, and subsequent disclosure are equally important, as they are unique and specific to each participant's world-view and environment.

Thus, if we look at the initial research question: "What are the psychological effects of the disclosure of a positive HIV diagnosis?" we can now begin to hazard some answers. The major psychological effects of the initial diagnosis seem to be anger, shock and disbelief and fear of stigma and discrimination. Interestingly, even after disclosure these emotions appear to persist – anger in particular did not go away merely because participants had disclosed. Thus, one of the psychological effects of disclosure was not to decrease anger. The emotions of shock and disbelief (perhaps better translated in this sense as a sense of injustice: "Why me?") also seem to have persisted following disclosure. It would also seem that, at least initially, the disclosure process actually heightened the fear of discrimination and stigma.

Once participants had disclosed, a particular type of acceptance did emerge. As has been previously stated this acceptance does not relate to a feeling of being at peace with the diagnosis, but rather involved a feeling of resignation to the inevitability of the process.

That is, the women had to accept the diagnosis in order to receive help at the clinic, and in that way the diagnosis had now become part of their daily lives.

In the next section, the question of the social effects of the participants' disclosure of their positive HIV diagnosis is discussed.

#### **4.2.9.1.6.2 Social effects of disclosure of a positive HIV diagnosis as identified by the three independent clinicians across five participant transcripts**

The majority of participants expressed that they were **satisfied with the support received following disclosure** of a positive HIV diagnosis. Support garnered following disclosure took various forms. Participant 1 reported receiving emotional support from her mother following disclosure. Participant 2 received both emotional as well as instrumental support from her younger sister following disclosure. Participant 3 expressed satisfaction with support received from a hospital support group for people living with HIV and AIDS. Participant 4 received emotional and instrumental support from her friend following disclosure. For the above-mentioned participants, disclosure of their positive HIV status proved beneficial in accessing much needed support and medical care, especially in the case of participant 2 who disclosed when her health was already visibly compromised.

**Lack of partner support following disclosure** was experienced by some participants in either married or committed relationships. Disclosure to a partner following a positive HIV diagnosis has been widely endorsed in reducing HIV and STI transmission and modifying behaviour in sexual practices. However, studies have shown that for women especially disclosure of a positive HIV diagnosis is not easy, for fear of a negative if not dire response from the partner. None of the women in this study reported a violent reaction from the partner following disclosure.

Some participants described **experiences of stigma/discrimination following disclosure**

of a positive HIV diagnosis from some family and community members. It can be hypothesized, that experiences of perceived lack of support and experiences of stigma/discrimination following disclosure of a positive HIV diagnosis, can lead to the re-emergence of the psychological responses following initial positive HIV diagnosis as discussed under section 4.2.9.1.6.

Thus, this information allows us to move towards a provisional answer to the question of the social effects of the disclosure of a positive HIV diagnosis. It is interesting that most of the women were satisfied with the support they received following disclosure. This indicates that, on a support-based level, the disclosure process was successful for these women as they were able to access the resources (both instrumental and emotional) that they needed. However, this support was not forthcoming from their partners, but was rather accessed from other areas. This indicates that, while support is available following disclosure, it does not necessarily come from the individual who is closest to the HIV infected individual (that is their partner). The experiences of stigma/discrimination indicate that the fear of stigma/discrimination (mentioned in the previous section) was not entirely misplaced. However, actual experiences of stigma/discrimination seem to appear less often than what they are feared.

### **4.3 OVERALL DISCUSSION AND CONCLUSION**

The aim of the research study was to investigate the psychosocial effects of disclosing a positive HIV diagnosis. The objectives of the study were to (a) explore the psychological effects on a sample of women following disclosure of a positive HIV diagnosis and to (b) explore the social effects on a sample of women following disclosure of a positive HIV diagnosis.

The overall picture that emerges from this research project is that there are inherent psychosocial effects (whether positive or negative) that impact on the disclosure of a positive HIV diagnosis, which begin to unravel when the individual first discovers that they are HIV positive.

Following a positive HIV diagnosis, there is a myriad of psychological responses that first have to be negotiated within the individual in adjusting to the positive HIV diagnosis prior to making the decision to disclose. In this study, the most common responses to the positive HIV diagnosis were anger, a fear of stigma/discrimination, shock and disbelief. These psychological responses to the diagnosis were also key in determining whether disclosure was delayed or completely avoided. For some participants disclosure of a positive HIV diagnosis was reserved or otherwise avoided, due to fears of stigma/discrimination. Following disclosure, feelings of anger and the fear of stigma/discrimination persisted. However, a type of acceptance became prominent, as the women set about dealing with the practicalities of the illness.

Some of the other psychological or emotional responses, such as self-blame and shame that arose following a positive HIV diagnosis were unique to each participant and largely influenced by various factors that define the participants' social spheres.

Disclosure of a positive HIV diagnosis was a source of distress for the majority of the participants, more so, in deciding who the disclosure target should be, and in anticipating the disclosure target's reaction. Disclosure targets were primarily female family members. This to some extent speaks of women being perceived as more likely to offer instrumental and emotional support. There is also evidence to suggest that female disclosure targets, depending on the quality of the relationship were seen to be more open and understanding prior to the disclosure of a positive HIV diagnosis. Other factors that can be ascribed to the choice of a discloser target were factors such as deterioration of health, concern for children's well-being, fear of death as well as the anticipation of a positive and supportive response following the disclosure. For the majority of the participants, one of the above-mentioned factors to a greater or lesser extent precipitated disclosure of a positive HIV diagnosis. Interestingly, the women frequently did not choose their partners as their initial disclosure targets.

Adjusting to one's positive HIV diagnosis is one of the factors that can be attributed to the length of time that passes between the initial diagnosis and the act of disclosure. Another factor that can be ascribed to the length of time between initial positive HIV diagnosis and disclosure is perceived social support, should disclosure take place. Thus, participants only disclosed their positive HIV diagnosis to those they felt would offer support.

Disclosure of a positive HIV diagnosis took place to garner not only instrumental support, but also in accessing the necessary care and treatment. It is interesting to note that the one participant, who disclosed immediately following her positive HIV diagnosis, is also the only one out of the five participants who was in a marital relationship with her partner. It can thus be hypothesized that the quality and type of relationship also plays a role in the disclosure process of a positive HIV diagnosis.

The psychosocial effects of disclosing a positive HIV diagnosis were both positive and negative. The majority of the participants were satisfied with the support received following their disclosure of a positive HIV diagnosis, with one participant experiencing satisfaction with support received from a hospital support group, following a perceived lack of support from family members following disclosure.

However, lack of partner support as well as experiences of stigma and/discrimination from some family and community members, following disclosure of a positive HIV diagnosis, in some instances were experienced, inducing significant psychological distress. Disclosure of a positive HIV diagnosis is based on a complex process of negotiating one's subjective responses to the HIV diagnosis and the fears that emanate from existing prejudicial perceptions around HIV and AIDS. Increasing community-based awareness campaigns that promote acceptance and openness about HIV and AIDS and supporting counseling would be promising approaches to increasing disclosure of a positive HIV diagnosis, so that much needed care and support can be accessed.

It remains important to note, however, that the disclosure of the positive HIV diagnosis does not serve as a universal panacea. That is, despite the fact that all the women in the study had disclosed, the emotional experiences of anger, depression and hopelessness persisted for most of the women. This is important because it points towards the complexity of the process of dealing with HIV/AIDS. The mere fact of disclosing, while providing much needed support, does not in and of itself ensure that HIV positive individuals emotionally adjust to their diagnosis.

The results from the current study suggest that the psychological responses following the diagnosis of a positive HIV diagnosis have a significant effect on the motivation to disclose in accessing much needed support. This suggests that the transition from the initial discovery of a positive HIV diagnosis to finding effective ways of coping and managing the disclosure process is fraught with discomfort and distress.

It is important that if all interventions and activities based on prevention of HIV are to be effective, particular focus should be paid to the manner in which people deal with and accept their positive HIV diagnosis. This also includes assisting disclosure targets, especially partners, in better coping with the impact of living with HIV and AIDS. Assisting individuals in better coping with the diagnosis is crucial in ensuring that the disclosure process is less threatening.

#### **4.4 Conclusion**

This chapter has presented and discussed the results of this research. In the final chapter, the limitations of the study are noted. Suggestions are also made for future research.

## **CHAPTER FIVE**

### **CONCLUSION**

#### **5.1 Introduction**

This chapter completes the research by discussing the limitations of the study, as well as providing recommendations for future research.

#### **5.2 Limitations**

Several methodological limitations of this study should be noted in interpreting the results. The sample size was small and therefore results cannot be generalized over different ethnic and socio-cultural groups of the HIV infected population in South Africa. This indicates the need to replicate the study with a larger sample of women.

Despite the use of three independent clinicians, the results of this research still retain a degree of subjectivity. This is an inevitable aspect of qualitative research. A quantitative study, which asked the same questions but which uses different techniques, might provide additional information.

It is also important that the findings of this study be placed in the context of the women that were interviewed. The described process may be unique to these women and

therefore not adequate for describing the disclosure process for the many women who are afflicted and affected by HIV and AIDS.

### **5.3 Recommendations**

This study has highlighted several areas of interest for future research. Possible future research questions could include:

- What interventions and strategies would be most effective in assisting women in first adjusting and accepting their positive HIV diagnosis, prior to disclosure?
- What interventions can better assist HIV positive women in negotiating their fear of stigma/discrimination following diagnosis?
- What interventions, therapeutic or otherwise can best assist women to better cope with and manage disclosure targets' reactions following disclosure?
- In maximizing quality of life of HIV positive women, do support groups for people living with HIV and AIDS have a significant role to play in offering much needed support?

In addition, another fascinating area of research suggested by these results is that of the response of the women's partners to their disclosures of positive HIV diagnoses. Thus, it would be interesting to conduct research on the partners of HIV positive women, to look at their reactions to the diagnosis, and the way in which they justify reacting. This would provide valuable insight into the process of non-support of HIV positive individuals. In

this way, research could be expanded to look not only at the HIV positive individual's motivations, but also at the motivations which drive those around them.

#### **5.4 Conclusion**

The results from this study suggest that the psychosocial effects of disclosing a positive HIV diagnosis can be both beneficial and detrimental. Disclosure of a positive HIV diagnosis can result in increased emotional and or instrumental support and improved psychological health. However, experiences with stigma/discrimination and lack of partner support following disclosure, experienced by some participants can prove harmful. In addition, the mere process of disclosure does not necessarily alleviate some of the negative psychological responses to the initial positive HIV diagnosis.

Communicating with one's partner prior to HIV testing might help women in anticipating the partner's reaction, giving them an opportunity to disclose the result, without the fear of adverse reactions. Disclosure of a positive HIV diagnosis should be viewed as a process that involves the gradual adjustment to living with HIV and AIDS, on the part of both the HIV infected individual and her disclosure targets.

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