

CHAPTER 1

INTRODUCTION

1.1 ORIENTATION TO THE STUDY

The Joint United Nations Programme on HIV/AIDS (UNAIDS, 2007) states that at the end of 2007, an estimated 33, 2 million people around the world were living with the human immunodeficiency virus (HIV). This figure includes the 2, 5 million people who acquired HIV during the course of 2007. The epidemic also claimed an estimated 2, 1 million lives in 2007, of which 76% occurred in Sub-Saharan Africa. Sub-Saharan Africa remains the most affected region and is home to about 22, 5 million of the total number of people living with HIV worldwide. South Africa is the country with the largest number of HIV infections in the world with AIDS remaining the leading cause of death.

In regions where the epidemic has been raging for years, more women are the worst affected and infected than men, and in countries where the epidemic is just beginning, new infections among women outnumber those among men (Bell, 2002). The majority of people living with HIV in Sub-Saharan Africa (61%) are among women (UNAIDS, 2007). Women in Africa are being infected at an earlier age than men and the gap in HIV prevalence between men and women continues to grow. There are, on average, 13 HIV-positive women for every 10 HIV-positive men. The difference in HIV infection levels between women and men is even more pronounced among young people aged 15 to 24. Driven by poverty and the desire for a better life, many women and girls find themselves using sex as a commodity in exchange for goods, services, money, accommodation or other basic necessities - often with older men. Social inequalities, poverty and migrant labour provide fertile ground for exploitative transactional and intergenerational sex in Southern Africa (UNAIDS, 2004).

Part of the reason for the rapid increase in female HIV infection is that it is physically easier for the women to contract HIV through intercourse than it is for men to get it from women (Ross, 2004).

Fredriksson and Kanabus (2004) express the view that HIV-positive women are treated very differently from men in many developing countries. Men are very likely to be "excused" for the behaviour that resulted in their infection, whereas women are not. In some African countries, women whose husbands died of acquired immunodeficiency syndrome (AIDS) or AIDS-related infections have been blamed for their husband's deaths.

AIDS currently overtaxes social systems. The rising death rate is immobilising the economies, education and health services of many countries; Africa is currently facing an orphan crisis unprecedented in human memory;

grandmothers are denied a peaceful old age by having to bury their children and care for their grandchildren; stigma and prejudice remain rife, making HIV infection and AIDS an unspeakable disease not to be named or talked about; and the rights of women and children are widely disregarded – leaving them disempowered and unable to protect themselves from HIV/AIDS (Van Dyk, 2005).

HIV/AIDS impedes the health and educational development that enables poor people (especially children) to escape poverty (UNAIDS, 2004). In health care systems in many countries are stretched beyond their limits as they have to deal not only with growing numbers of AIDS patients, but also with the loss of health personnel. Women in general and girls in particular are more vulnerable to HIV/AIDS and are disproportionately affected by the epidemic. Females also bear the greatest burden of care for family members who are infected (International Community of Women Living with HIV/AIDS/ICW, 2003). Some families often remove girls from school to care for sick relatives or assume family responsibilities (Palitza, 2005), thereby jeopardising recent gains in female health, nutrition and education (Canadian International Development Agency/CIDA, 2004; Community Workers Co-operative/CWC, 2003). In education, teachers and students are dying or leaving school, which reduces both the quality and efficiency of educational systems. This trend has an especially detrimental impact on the girls' own development and leaves them more vulnerable to the epidemic. Girls who have not completed their schooling are less likely to obtain the earning power to increase their economic independence and are more likely to resort to transactional sex in order to survive. Reduced education for women also impedes national development (CWC, 2003).

Women and girls in the developing world are increasingly becoming HIV/AIDS' main victims and current safe-sex prevention strategies are of little use to the millions who do not have the power to say 'no' to sex or to insist on condom use (Centers for Disease Control and Prevention/CDC, 2001; ICW, 2004; Lawrence, Brasfield, Jefferson, Alleyne, O'Bannon III & Shirley, 1995; Ross, 2004). It is under such circumstances that researchers can make use of the lessons learned in developed countries, but the African HIV/AIDS epidemic should be approached from an African perspective. A cultural norm such as the community's acceptance of polygamy encourages males to have multiple sexual partners, which inevitably contributes to the rising rates of HIV infection and place South African women at risk for contracting HIV (Abdool Karim, 2005).

The inequality women face - from poverty and stunted education, to rape and denial of women's inheritance and property rights - is a major obstacle to victory over the virus (Ross, 2004).

Married women in some African countries are in greater danger of contracting HIV than unmarried ones, because women often marry men who are much older

than themselves – for the sake of financial security – and these men are sexually more experienced and therefore more exposed to HIV. Women's position in relationships also exposes them more to HIV (Ross, 2004), because their status is inferior to that of men. They have very little control over their sexual lives and over ways of preventing sexually transmitted infections, which makes it much easier for them to contract HIV.

According to the International Center for Research on Women/ICRW (2002a), the HIV/AIDS epidemic has from the beginning been accompanied by an epidemic of fear, ignorance, blame, isolation, uncertainty, misperception and denial of HIV/AIDS (Awusabo-Asare, 2000; LeBlanc, London & Aneshensel, 2000; Whelan, 2002). This leads to the stigmatisation of and discrimination against both the people living with HIV/AIDS and their family members (De Bruyn, 1999; Wardlaw, 2000).

The stigma related to HIV is a major barrier in addressing the HIV/AIDS pandemic because it has a negative effect on all aspects of prevention, diagnosis, treatment and care (Deacon, Stephney & Prosalendis, 2005; Bond, Chase & Aggleton, 2002). The stigma has an impact on the behaviour of HIV-infected people and the choices they make. Earlier in the epidemic it was found that in some African communities people were more fearful of the social consequences of AIDS than of the disease itself (Lie & Biswalo, 1994). The fear of HIV/AIDS is still prevalent in a country like South Africa. Parker and Aggleton (2003) agree that since HIV/AIDS first appeared in the 1980s, it has been associated with fear, stigmatisation and discrimination.

During the years discrimination has become more subtle and less explicit. In the past, for example, people may have been fired outright when it was discovered that they were HIV positive. Today they may be laid off for "other reasons", or they may be harassed and pressured to the point that they leave their employment or go on early pension (De Bruyn, 1999). Fear of being identified at work and of losing their employment even prevents some people from taking HIV-related medications (Hubley, 2002; ICRW, 2002a; 2002b).

1.2 MOTIVATION FOR THE STUDY

An HIV diagnosis is a serious life crisis that requires considerable coping resources. When receiving an HIV diagnosis, people have to deal with issues such as death, HIV-related symptoms, change in life expectancy, change in body image, disclosure, mistrust in their relationships, stigma, possible social isolation and rejection (Hudson, Lee, Miramontes & Portillo, 2001).

Various aspects can prevent women from getting the treatment that they may need such as the stigma attached to HIV/AIDS, inaccessibility of clinics, lack of money and too many other responsibilities (CIDA, 2004). Negative attitudes of

health workers towards women presenting with HIV/AIDS may be another measure that acts as a deterrent to their seeking treatment (Hubley, 2002; ICRW, 2002a; 2002b) or even contraceptives.

The dominance of male needs and the denial of female needs impede open discussion between the sexes and limit people's chances of mutually satisfying, respectful and safe forms of sexual behaviour. To curb HIV transmission, both partners should be able to express their worries about infection and use protective measures such as condoms. This should follow out of respect and affection, rather than to be a sign of mistrust (CIDA, 2004).

Combating the stigma and discrimination suffered by people who are affected by HIV/AIDS is as important as developing medical cures to prevent and control the global epidemic, and assisting HIV-positive people to deal with stigmatising attitudes (Fredriksson & Kanabus, 2004).

Because stigma has an impact on prevention and care, it is important to address it (Siyam'kela, 2004). The magnitude of stigma has had a seriously detrimental effect on HIV/AIDS testing (CDC, 2001).

The above observations are particularly true for the people living with HIV/AIDS whom the researcher observed while working at the Witbank Hospital. As a result of the various phases in a person's adaptation to the disease, a clinical psychologist who is a member of a multi-disciplinary team would assist the patient to comply with his/her treatment and come to terms with this chronic illness. Because of the negative experiences following an HIV diagnosis such as being rejected by significant people, the stigma has a negative impact on the behaviour of HIV-positive people and the choices they make. As a result, they need to understand their experiences in order to deal with stigma. An intervention model that was developed as part of the current study assisted HIV-positive women in coping with their own disease.

There is insufficient documented research that investigates the nature and level of stigma that HIV-positive people experience (Visser & Makin, 2004). The majority of the research conducted in this field has been carried out from a western perspective (Van Dyk, 1992). In a country like South Africa, where HIV/AIDS has such an enormous impact, it is important that interventions be developed within the context of the African HIV/AIDS epidemic. Hence the need for this study to investigate and understand how women living with HIV/AIDS experience stigma and how to change their experience of internalised stigma and discrimination.

This study aims at developing a therapeutic intervention model to assist HIV-positive women in understanding their disease, to change the experience of coping with internalised stigma and discrimination, and to empower people living with HIV/AIDS with more adaptive ways of thinking and behaving. It will be

crucial in seeking treatment, adherence to treatment and the adaptation of the women - as well as in understanding their psychological needs.

Cognitive behaviour therapy (CBT) was used to address the internalised stigma and discrimination that HIV-positive women experience. In order to change the way patients think and to promote more realistic and adaptive ways of thinking, cognitive and behavioural methods are used to challenge dysfunctional beliefs (Bea & Tesar, 2002; Beck & Weishaar, 1989; Meyer & Salmon, 1988; Plotnik, 2002; Weiten, 2002; Wilson, 1989). Beck and Weishaar (1989) emphasise that cognitive change can promote behavioural change by allowing the patient to take risks. In turn, experience in applying new behaviours can validate new perspectives.

Through both cognitive and behavioural methods, the patient discovers more adaptive ways of thinking and behaving. The therapist helps patients to see how unrealistically negative the thoughts are, and therefore persuades them to alter their patterns of thinking (Bea & Tesar, 2002; Weiten, 2002). HIV-positive women may for example have “irrational” feelings of failure and worthlessness, which can be addressed and modified according to Wiser, Goldfried, Raue and Vakoch (1996). Thus, this was the theoretical perspective that was utilised in therapy to assist HIV-positive women in dealing with stigma. Through this approach, the patient could learn how to correct faulty cognitive processing so that it would eventually no longer be necessary to depend on the therapist (Bea & Tesar, 2002; Beck & Weishaar, 1989; Kelly, 1987; Wilson, 1989).

Cognitive therapy maintains that the modification of dysfunctional assumptions leads to effective cognitive, emotional and behavioural change. Cognitive therapy is a present-centred, directive, active and problem-orientated approach best suited for cases in which problems can be delineated and cognitive distortions are apparent (Beck & Weishaar, 1989; Plotnik, 2002). The researcher used this approach to develop and assess an intervention model for changing the experience of internalised stigma and discrimination of women living with HIV/AIDS.

1.3 AIM OF THE STUDY

This study aimed to develop and evaluate an intervention model by using an individual cognitive behaviour technique. The objective was to change the experience of internalised stigma and discrimination of women living with HIV/AIDS. Knowledge of this intervention model may enable psychologists to understand HIV-positive people’s experiences of internalised stigma and assist the female patients in coping with their disease. The knowledge gained could be of value in terms of assisting infected people to change the experience of internalised stigma and discrimination, and to enable them to come to terms with this potentially life-threatening disease.

1.4 THE OUTLINE OF THE STUDY

In order to enable the reader to understand how to change the experience of internalised stigma and discrimination of women living with HIV/AIDS, this study was structured as follows:

- Chapter 2 dealt with a review of the literature on HIV/AIDS, stigma and discrimination, which included a definition of key concepts such as the following: signs, symptoms and transmission; the stages of adjustment to the disease; why women are in a negative position; women's emotional experiences of being HIV positive; responding to HIV/AIDS stigma and discrimination.
- In Chapter 3 the researcher focused on theoretical perspectives on how to facilitate change through therapy and especially how to help women to change their experience of stigma.
- Chapter 4 reports on the method of investigation, qualitative and quantitative research, the researcher's role, research design, measuring instruments as well as the method that was used for analysing data.
- Chapter 5 presents the findings of data.
- Chapter 6 contains a discussion of the results and their integration with literature, as well as the conclusion and evaluation of this study, based on the findings of this research. Possible recommendations were made, which may encourage further investigations of stigma related to HIV/AIDS. Possible research projects that could emanate from this research were also suggested.
- Finally, the sources consulted, as well as relevant appendices were listed.

CHAPTER 2

REVIEW OF THE LITERATURE ON HIV/AIDS, STIGMA AND DISCRIMINATION

2.1 INTRODUCTION

Until 1982, no one had heard of AIDS. However, since then it has become one of the most feared diseases in history and has killed millions of people, most of them young or middle-aged. Millions more are infected with HIV – the virus that causes AIDS. Because people with HIV are infectious to others for the rest of their lives, the number of infected people is growing all the time (Whelan, 2002).

In this chapter, the researcher provides an overview of HIV transmission and the impact thereof on the body, which includes the various stages of the illness (biological) that HIV-positive women in this research go through. This is followed by a discussion of the experience of stigma and discrimination (social), together with the women's emotional experience (psychological) when diagnosed as HIV positive. In addition, responses to HIV/AIDS stigma and discrimination are described.

2.2 HIV TRANSMISSION

HIV is present in all the body fluids of an infected person but is concentrated in blood, semen and vaginal fluids. It is present in virtually all body tissues and organs, including the brain, spinal cord, cerebrospinal fluid and breast milk. It can be found in tears and saliva, although these are not considered significant routes of transmission (Hubley, 2002).

Many people are afraid of HIV and AIDS. However, the good news is that it does not easily spread from person to person. Viruses such as those of the common cold or influenza are tough viruses that are able to withstand being blown around in the air and are highly infectious. HIV, on the other hand, is a delicate virus that is easily killed by heat and by drying. A larger dose of virus is needed to spread HIV than other viruses that are spread in a similar way such as Hepatitis B. Four critical conditions must be fulfilled if HIV is to be spread by a particular route:

- HIV must be present in a body fluid such as semen, vaginal fluids, blood or blood products.
- HIV must survive during the period that it is out of the body - this can be a long time in stored blood, but is quite short in most other situations.

- HIV must get into the blood of another person. Skin forms a barrier to HIV, therefore, the virus must enter where the skin is damaged or more delicate, for example through the mucous membranes of the anus and vagina. The acid in the stomach also inactivates the virus.
- Sufficient HIV must be transferred into the other person to make an infective dose (Hubley, 2002).

Therefore, HIV is generally transmitted in three ways: 1) Through sexual intercourse; 2) when HIV-infected blood is passed directly into the body, and 3) from mother to child during pregnancy, childbirth and breast-feeding (De Cock, 1996; DiPentima & Steven, 2005; Evian, 1991; 2003; Hubley, 2002; Klatt, 2005; Mather, 2002; Mayo Foundation for Medical Education and Research (MFMER), 2004; Whelan, 2002).

A person is most likely to pass on the HIV virus to someone else soon after becoming infected with the virus (during the first four to eight weeks), when there is a high HIV viral load, or during the later phases of the infection when symptoms of HIV infection or AIDS appear. This is because there are larger quantities of virus in the blood stream at these times. It is important to note that it is possible to spread HIV at any time during the disease (Evian, 2003).

2.2.1 The Influence of Poverty and Low Socio-economic Conditions

AIDS and other sexually transmitted infections (STIs) are often more common in developing countries. The reasons why low socio-economic conditions promote the spread of STIs (according to Evian, 2003) are as follows:

- Poverty often contributes to the sexual exploitation of women, as they culturally have a more inferior status than men. In many communities, women have very little control over their sexual lives and any attempts to prevent STIs, which in turn give rise to HIV transmission. Women are often forced to engage in transactional sex to earn precious money for food and basic needs, and to help raise their children. Even young girls may sell sex to older men (Natrass, 2004).
- Large-scale unemployment promotes migrant work and family disharmony. This forces people to leave their homes and loved ones, friends and local community life. In the far away places, migrants often find themselves in lonely, unfavourable, hostile or alienating environments. There is a natural need for sex and intimacy, which results in multiple-partner sexual relationships (Natrass, 2004).
- People in poor living conditions often do not have easy access to health care services, and STIs often go untreated and thus spread more easily.
- Poor education and low literacy levels help to keep people ignorant of the ways and means to avoid HIV/AIDS (Natrass, 2004).

- Alcoholism, smoking dagga or the use of drugs to escape everyday hardships can contribute to irresponsible behaviour, resulting in sex with multiple partners.
- Crime and violence are also common in cities and towns and these cause further stress to family and community life.
- Many of the problems discussed above also result in the breakdown of the traditions, customs, beliefs and cultural practises in a community. These practises usually determine the accepted sexual behaviour and constraints in a society. When they have collapsed, it often results in people having multiple sexual partners and practising indiscriminate sex.

2.3 THE IMPACT OF HIV ON THE BODY

Once the human immunodeficiency virus enters the human body, it attaches itself to a white blood cell (WBC). WBCs are those blood cells known as leucocytes that function as part of the immune system and are called CD4 cells. They are the T helper/inducer lymphocytes with CD4 receptors and are important cells that regulate and control aspects of the immune system. They are also called the T4 helper cells and are the main fighters of disease in the body. Whenever there is an infection, CD4 cells lead the infection-fighting army of the body to protect it from falling sick. Damage of these cells can affect a person's disease-fighting capability and general health (United Nations Development Programme /UNDP, 2005).

After gaining a foothold in the CD4 cell, the virus injects its RNA into the cell. The RNA then gets attached to the DNA of the host cell and becomes part of the cell's genetic material. This implies a virtual takeover of the cell. Using the cell's division mechanism, the virus now replicates and produces in large quantities hundreds of thousands of its own copies. These cells then enter the blood stream, get attached to other CD4 cells and continue replicating. As a result, the number of the virus in the blood rises and that of the CD4 cells declines.

Current estimates are that one third of people with HIV are not aware of it yet (Wanted, 2005). A person who becomes infected with HIV will usually pass through various clinical stages that occur over a period of five to 12 years (Evian, 2003). The stages include the asymptomatic phase, when the person has the virus but is well and displays no symptoms of the disease (asymptomatic). During the symptomatic phase, the person experiences mild disease episodes to severe illness (symptomatic), and finally the person dies (details to be discussed in the next section).

HIV slowly damages the immune system and the appearance and manifestation of disease is usually related to the degree of immunodeficiency and the viral load in the body. Anti-retroviral drug therapy (ART) involves the use of drugs that

suppress or prevent replication of HIV, thus significantly changing the course of the disease and prolonging the well and asymptomatic phase. The state of the immune system or that part of the body's structure and function that fights against infections and other foreign recognised bodies, is the best predictor of the patient's risk of developing symptomatic disease. Measuring the number of CD4 cells is currently regarded as the best indicator of immunodeficiency or a weakening in the immune system, in HIV disease and is used to monitor the immune status of the person.

In the absence of the CD4 count, the lymphocyte count can also be helpful – however, it is less specific and less accurate. Even in the absence of these tests, one may rely on the presence of HIV-related signs and symptoms. These include thrush, shingles and Kaposi's sarcoma as indicators of advanced immunodeficiency. AIDS is the advanced, late and final stage of HIV infection and is associated with severe immunodeficiency (Evian, 2003; UNDP, 2005).

The viral load usually rises to a high level soon after HIV infection. This is due to a very rapid multiplication and replication of the virus after infection. As the body develops antibodies to HIV, the virus level in the blood decreases, as the virus is mainly swept into the lymph nodes. The decline in the HIV load usually coincides with the time of sero-conversion and the primary HIV infection. Viral load levels can vary between “undetectable” levels to values exceeding two to three million “copies” per ml of blood (Evian, 2003). Levels below 50 (or even lower) are considered “undetectable”. Although disease progression may differ between people and situations, a typical progression will be described in more detail in the following section.

2.3.1 Primary or Early HIV Infection

In the first three to six months after acquiring HIV infection, there may be a short (one to two weeks) sero-conversion illness, which can cause the following symptoms: fever and headache; tiredness, malaise, arthralgia or myalgia and depression; rash; pharyngitis (sore throat); muscle and joint pains; swollen lymph glands; gastro-intestinal symptoms (such as nausea and diarrhoea) (Alcamo, 1997; DiPentima & Steven, 2005; Dixon, 2002; Evian, 2003; Gilson, 1996; Huble, 2002; Klatt, 2005; MFMER, 2004; UNDP, 2005; Wanted, 2005; Whelan, 2002).

This occurs at the time when the HIV antibody test usually converts from being negative to positive. The clinical condition is then referred to as sero-conversion illness. The sero-conversion illness is often mistaken for a “flu-like”, viral illness or glandular fever, because the signs and symptoms are non-specific. It often passes unnoticed by the person. The HIV anti-body test usually becomes positive four to six weeks after infection. Often, for the first one to five years or more, the HIV test may be the only indication that a person has HIV, with no other signs of illness (Evian, 2003).

The patient usually remains well and asymptomatic, after the initial non-specific symptoms of HIV infection and sero-conversion. This period is referred to as the clinically latent or “silent” phase of HIV infection. The HIV viral load may rise to high levels before the sero-conversion stage and then drop to much lower levels afterwards (Evian, 2003).

The level that the viral load reaches at this stage of the disease is called the “set point” and ART can reduce this set point. It must be pointed out that ART for primary infection are no longer recommended as it was considered in experimental groups in 2003 but was then discontinued as it was regarded by many scientists as irresponsible. A lower set point is likely to result in a lowered viral load in the body and a better prognosis. This “early detection” of HIV is often missed in most patients. It is especially important to be tested after needle stick injuries, rape and other known risky sexual encounters (Evian, 2003). In post-exposure prophylaxis, the individual is not infected by HIV yet and the purpose of the ARVs is to prevent the virus to take hold. The clinically latent or “silent” infection phase will be discussed next.

2.3.2 Clinically Latent or “Silent” Infection – the Asymptomatic Phase

HIV-infected people usually experience a period of good health in which the virus remains clinically “silent” or latent. This phase may last three to seven years (even up to 10 years) (Evian, 2003; UNDP, 2005). Some people stay asymptomatic for anything from one to 15 years, with 10 years being the average in the developed world. However, even though the infection is clinically “silent”, the virus is active in the body and usually causes progressive damage to the immune system. The person is also able to spread the virus during this phase. The CD4 cell count will usually decrease by between 40 and 80 cells per ml of blood per year (Whelan, 2002). The asymptomatic phase is associated with a CD4 cell count of between 500 and 800 cells per ml and even less (Alcamo, 1997; Evian, 2003).

2.3.3 Minor HIV-related Symptoms – the Minor Symptomatic Phase

Between three and seven years after the HIV infection, some patients may develop “minor” signs and symptoms secondary to the infection. These signs and symptoms may include the following: chronic swelling of the lymph nodes – referred to as “persistent generalised lymphadenopathy”/PGL; herpes zoster (shingles); occasional fevers; skin rashes; fungal nail infections; recurrent oral ulcerations, angular stomatitis and cheilitis; recurrent upper respiratory tract infections (Dixon, 2002; Evian, 2003; Hubley, 2002).

The minor symptomatic phase is usually associated with a CD4 cell count of between 350 and 500 cells per ml of blood. The symptomatic phase is described in the following section.

2.3.4 HIV-related Disease – the Symptomatic Phase

After about five to eight years following the HIV infection, the viral load tends to increase progressively. The immune system continues to deteriorate and become deficient. Signs of more HIV-related diseases begin to appear. These signs and symptoms are usually due to overgrowth of some of the body's natural flora with fungal infection and re-activation of old infections (for example, TB and herpes). They are also due to the uncontrolled multiplication of HIV itself. Later, as the immunodeficiency progresses, more frequent and severe opportunistic infections start to occur. Opportunistic infections are illnesses of the body as a result of a weakening of the body's defence. Normally, these infections would not cause a particular disease in a healthy body. This stage of the HIV disease is formally referred to as "AIDS-related complex" (ARC).

Common signs and symptoms of the symptomatic phase are: oropharyngeal candidiasis or vaginal candida infection (thrush); hairy leukoplakia on the tongue; recurrent herpes simplex infection; herpes zoster; acne like bacterial skin infections; persistent and unexplained fevers and night sweats; skin rashes; generalised lymphadenopathy or shrinking of previously enlarged lymph nodes; persistent diarrhoea; cough and shortness of breath; weight loss. The reactivation of TB may also be associated with this stage of infection.

The symptomatic phase is usually associated with a CD4 cell count of between 150 and 350 cells per ml of blood (Evian, 2003; Hubley, 2002; MFMER, 2004; Wanted, 2005). The following section discusses AIDS, the severe HIV-related disease.

2.3.5 Severe HIV-related Disease – AIDS, the Severe Symptomatic Phase

The symptomatic phase usually progresses over the next year or 18 months into the fully developed AIDS phase of the disease. AIDS is associated with a high HIV viral load and severe immunodeficiency. These usually correspond to a CD4 cell count of below 200 cells per ml and to a low lymphocyte count. This allows the development of severe opportunistic infections such as cancers and HIV-related organ damage. These conditions are therefore known as "AIDS defining" illnesses (Evian, 2003; Klatt, 2005; Whelan, 2002). It is at this stage of the disease that the South African government has agreed to provide public hospital patients with ART.

The signs and symptoms of AIDS differ from one patient to the next, depending on which cancer or organ is affected, and are as follows: herpes; seborrhoeic dermatitis; chronic pelvic inflammatory disease (PID); respiratory infection; pneumonia; candidiasis – oral or genital thrush; bowel infection; brain infection; cancers such as Kaposi's sarcoma. Lymphoma may present with enlarged lymph nodes, liver or spleen; lack of energy; severe tiredness, fatigue and weakness; difficulty in sleeping; memory and concentration loss; lack of co-ordination and

personality changes; anxiety and depression – due to suffering and pain; peripheral neuropathy; wasting of body tissue and marked weight loss; difficulty with and pain on swallowing; retinitis and blindness (Alcama, 1997; DiPentima & Steven, 2005; Dixon, 2002; Evian, 2003; Gilson, 1996; Hubley, 2002; MFMER, 2004; UNDP, 2005; Wanted, 2005; Whelan, 2002).

It is clear from the above that AIDS is not a single disease with a characteristic set of signs and symptoms. It consists of and may present with a variety of signs and symptoms, depending on which specific infection or cancer is present. It also depends on which organ is mostly affected. These conditions usually occur late in the course of HIV infection and arise due to the deteriorating immunodeficiency.

AIDS patients often go through stages of being very sick to being reasonably well again (usually due to ART). However, infections tend to re-occur and become more frequent. The body becomes progressively weaker with repeated infection, due to the multiplication of HIV and possibly the development of several cancers. After developing signs and symptoms of AIDS, death usually occurs six months to three years or later (Evian, 2003).

The availability of ART and the prevention and treatment of the opportunistic infections (such as TB, pneumocystis jiroveci pneumonia, candidiasis) can modify the progress of the disease. The patient's wellness can be significantly prolonged by modern ART, which can reduce the severity and frequency of opportunistic infections (Evian, 2003; Whelan, 2002). The women who participate in this research all are on ARV's in a public hospital – that means that they have been through all of these stages and were already sick with a CD4 count below 200. It is thus relevant to understand what they experienced or are experiencing when working with them in therapy. The next section will focus on a discussion about whether every person with HIV can go on to develop AIDS.

2.3.6 Stages of Development of HIV Infection into AIDS

It is not clear whether every HIV-infected patient will progress to develop illness and AIDS. Through the past twenty years it has been found that HIV-infected patients can be rapid or slow progressors (Evian, 2003).

Rapid progressors are people who usually develop immunodeficiency earlier, often within five to seven years after infection. For some, this may be as soon as within three to four years.

Slow progressors generally remain well and active without any disease, and with very little or absent immunodeficiency. They may remain well for 10 to 15 years or more.

Almost 80% of HIV-infected people will have developed AIDS within 12 years of acquiring the infection. On average, it takes about eight years for HIV to progress into AIDS. It seems more likely that most HIV-infected patients will eventually develop severe immunodeficiency and symptomatic disease, but for some it can take up to 15 to 20 years.

Non-progressors are a small percentage of infected people (almost 5%) who remain well and free of immunodeficiency. They may never progress to immunodeficiency and HIV-related illness. Researchers are especially interested to find out why some people's HIV does not progress into AIDS.

The existing health status of a person may influence how long it will take to develop immunodeficiency and symptomatic disease. Diseases like malnutrition, measles, TB and malaria may have an independent immune-depressive effect. This may alter the natural course of the HIV disease (Evian, 2003). Studies suggest that the rate of progression to AIDS is faster in developing countries. This may be because people in these countries are much more exposed to common infectious diseases (Hubley, 2002).

In the previous section, the researcher dealt with the signs and symptoms of HIV/AIDS to promote an understanding of what the women in the study may experience. The researcher will also discuss the emotional reactions of women when diagnosed with HIV, as the present study focused on helping women to deal with these experiences.

2.4 EMOTIONAL EXPERIENCES OF BEING HIV-POSITIVE

In a study conducted in Pretoria by Mokhoka (2000), women who were diagnosed with HIV experienced different types of emotions. Their initial reaction was shock and disbelief. It was difficult for the women to accept the fact that they had to live with HIV.

Anger as a psychological reaction to the onset of chronic illness is often generated by feelings of frustration associated with the illness (Westbrooke & Viney, 1982). Anger is a typical response to the unexpected loss of control over one's life (Giddens & Giddens, 2000). In this case, anger seemed to be mainly directed at the people who were thought to be responsible for infecting the women (Kalichman, 1995). The difference in verbalising and admitting to these feelings of anger seemed to be related to the type of relationship between the women and the persons who infected them (Westbrooke & Viney, 1982).

Anger was often displaced in all directions and projected onto the environment – at times almost random (Kübler-Ross, 1969). Family members who were not thought to be supportive can also be at the receiving end of women's anger.

When a person is diagnosed with HIV, he/she immediately thinks of death. From that moment, that person will also be grieving and mourning some loss, which can be the loss of life associated with an anticipation of death, or loss of time as a result of the now limited life span. Simos (1979) views anger as an integral part of the grieving process. Hate feelings were found to be closely related to anger, with hate also being directed at people who were thought to have infected the participants (Mokhoka, 2000).

These emotional reactions also included feelings of self-blame and guilt for having been infected (Mokhoka, 2000). Self-blame, shame and self-devaluation are among the first emotional responses of a person who is diagnosed with HIV (Chuang, Jason, Pajurkova & Gill, 1992). This type of emotional response is common in women, due to the perception that if they are infected with HIV, they are promiscuous. Guilt feelings also originate from the thought of dying and leaving one's children behind (Bennett, 1990). These feelings can account for much of the pain of the process of mourning (Simos, 1979). Giddens and Giddens (2000) agree that not being in control over a situation can leave one feeling powerless.

Apart from worrying about themselves and their health, women interviewed by Mokhoka (2000) are indicated to have said they have worries about leaving their children behind, which was very hurtful to them. In cases where there is nobody to take care of their children after the parents have passed away, the children's well-being seemed to be the most significant issue on the mother's mind. The thought of bringing shame on their families when the news becomes known to everybody was also painful. Financial factors consequently play a major role in the women's state of mind. Uncertainty about the future in the sense of not knowing how long they still have to live, means they must start saving money for their children.

There were references to sadness and a depressed mood during the interviews conducted by Mokhoka (2000). Depression may be a way of shutting down the emotional system so that it doesn't suffer a dangerous overload (Giddens & Giddens, 2000). For patients living with HIV/AIDS, depression is a common, distressing condition that can interfere with critical self-care behaviour – adherence to antiretroviral therapy (Safren, Hendriksen, Mayer, Mimiaga, Pickard & Otto, 2004). During these phases of depression women felt hopeless and helpless, and just wanted to commit suicide, thinking that they were going to die anyway. Suicide is seen as a way to escape inner pain and depression, rather than working through problems (Giddens & Giddens, 2000). Knowing the facts about the virus and the progression of the disease helped them to understand that they can still live with the virus for a long time, as long as they take proper care of themselves.

Some women mentioned feeling worthless and ashamed of themselves soon after they were diagnosed. The reactions they received from others further

reinforced those feelings (Mokhoka, 2000). People's perception of HIV somehow influences the way HIV-infected people perceive themselves (Siegel, Karus, Raveis & Hagen, 1998). The women seemed to be worried about the way they appear physically, and they attempted to maintain weight in an endeavour to steer attention away from their physical appearance and quell suspicions about their HIV status. They therefore ensured that they would eat enough to be able to retain their body weight. It was essential to the women that people should not be able to tell that they are HIV positive by looking at them.

When pronounced HIV positive, many people feel completely hopeless, as they believe that there are very few options open to them (Orr, 2000). They feel as though their death certificate has been signed and that all they have left to do is to wait to die (Dharapak, 2005). Their feelings of despair are multiplied by the stigma, ignorance and often violence, which continue to underpin the epidemic. People living with HIV/AIDS have had to face being cast out of their families and communities. They have been assaulted both physically and emotionally when having opted to disclose their status (Orr, 2000).

It is of importance to recognise not only the powerful influence of the individual's immediate familial or social context, but also the broader impact of the larger social climate – particularly the negative effects of social stigma, fear of rejection and discrimination (Kaminsky, Kurtines, Hervis, Millon, Blaney & Szpacznik, 1989). According to Mokhoka (2000) women experienced difficulty in sharing the diagnosis with their partners. It seemed easier if the partner knew about his own status already or they discussed getting tested. In cases where the partners did not know, women feared telling them because they were afraid of being rejected. This finding is also confirmed by Simoni, Mason, Marks, Ruiz, Reed and Richardson (1995), who state that individuals contemplating disclosure may also fear a disruption in relationships, particularly by evoking stigmatising attitudes.

It seems that the common perception among men is that if their female partner first tests HIV positive, she must have contracted the virus from elsewhere. When men became the ones to undergo HIV testing first, the women usually found themselves forced to forgive them and care for them. Some women stay with their men because they are dependent on them financially and sometimes have nowhere else to go if they should leave their partners (Paterson, 1996).

The type of treatment that women received from their families determined the way they related to them afterwards. Loss of interpersonal contact, especially with important people like family members, leaves a person with feelings of isolation (Manuel, Roth, Keefe & Brantley, 1987).

2.5 HIV/AIDS STIGMA AND DISCRIMINATION

Siyam'kela (2004) defines stigma as a powerful and discrediting social label that radically changes the way individuals view themselves and are viewed as

persons. Discrimination is the immediate process of applying the stigma at a behavioural or community level (Visser & Makin, 2004). According to Goffman (1963), stigma can be classified as follows:

- Felt or internalised stigma refers to the person's experience of, or fear of being stigmatised. This is a construction of the person and represents the stigma internalised by the affected person. Stigma leads to unwillingness to seek help and access resources (Siyam'kela, 2004). The researcher focused on this form of stigma in his study in order to develop a therapeutic individual cognitive behavioural technique to assist women living with HIV/AIDS to change the experience of internalised stigma.
- Enacted (external) stigma refers to the actual experiences of stigmatisation and incidences of discrimination experienced by the affected person. Many other factors including stigma provides access to discrimination on the basis of HIV status or association with someone who is living with HIV (Siyam'kela, 2004).
- Perceived community stigma refers to the perception a person has of the community's stigmatising attitudes (Goffman, 1963). It was found that HIV-positive women perceive the community to be very negative, although they do not experience high enacted stigma. Thus the question is asked whether the perception of stigma is not overrated in these communities of Atteridgeville and Mamelodi in the Tshwane area (Visser, Kershaw, Makin & Forsyth, 2008). Scambler and Hopkins (1986) also argue that the internalised stigma often precedes rather than results from the enacted stigma. They claim that many individuals reduce the opportunities for enacted stigma in order to protect themselves from discriminatory actions. People with HIV therefore fear to reveal their status and may withdraw from society because they expect that other people will reject them, irrespective of the enacted or real community stigma.

There are four main reasons why stigma is attached to HIV/AIDS (Alonzo & Reynolds, 1995; Parker, Aggleton, Attawell, Pulerwits & Brown, 2002):

- HIV/AIDS is a life-threatening disease, which is perceived as contagious and threatening to the community.
- People are afraid of contracting HIV through casual contact. This is possibly due to lack of information and misconceptions.
- HIV/AIDS is associated with behaviour that is already stigmatised such as sexual promiscuity and drug use – behaviour that is not sanctioned by religious and moral beliefs. That probably results in the perception that HIV/AIDS is the result of deviant behaviour deserving punishment.
- People living with HIV/AIDS are often seen as being responsible for having contracted the disease, which increases the attribution of stigma.

The stigma is therefore born of fear, ignorance, lack of knowledge and social judgement.

The stigma and discrimination perpetuate the culture of silence and fear that surrounds the disease and can prevent individuals from being tested and treated for HIV/AIDS and associated infections. The destructiveness of HIV-related stigma is further compounded by the fact that the status of many people living with HIV/AIDS is already marginalised due to poverty, involvement in sex work, drug use, or other stigmatised activities. In addition, many more who do not know their HIV status live in fear of facing stigma and discrimination, should they contract the disease. HIV-related stigma is increasingly recognised as the single greatest challenge to slowing the spread of the disease. In spite of the increasing awareness that the impact of stigma must be addressed in policies and programmes that are aimed at reducing HIV/AIDS, efforts are impeded by the scarcity of information on stigma and HIV/AIDS. If people can reduce the fear surrounding the risk of contracting HIV/AIDS or its effects, they can be able to reduce stigma. Clearly, some degree of fear of infection, coupled with knowledge about what is likely to transmit the disease and how to prevent this, is important in maintaining people's ability to prevent themselves from being infected. HIV/AIDS-related stigma and resulting discriminatory acts create circumstances that fuel the spread of HIV (CIDA, 2004; Corish, 2005; ICW, 2004; ICRW, 2002b; Keeton, 1999; Siyam'kela, 2004).

In a study conducted by Visser, Makin, Vandormael, Sikkema and Forsyth (in press), a comparison is made of the level of stigmatising attitudes among members of Atteridgeville and Mamelodi communities and what they perceive the level of stigma to be within their communities. The researchers also attempted to determine the relative contributions of socio-demographic characteristics, cultural beliefs and exposure to HIV to stigmatising attitudes. The findings revealed that the level of internalised stigma was significantly lower than perceived levels of community stigma. Participants who were more stigmatising were older, male, less educated and were less knowledgeable about HIV. They were also less likely to know someone with HIV and held onto more traditional cultural view points. While socio-demographic and cultural factors are difficult to change, efforts aimed at increasing people's knowledge and exposure to the epidemic in their community could change the level of stigmatising attitudes within their community. This could have the potential advantage of addressing the epidemic and providing greater support for those living with HIV/AIDS.

It is significant for those who are HIV positive to know that HIV stigma is probably not as prevalent as commonly perceived, and therefore others may be more accepting and supportive than HIV-positive people may anticipate. In actual fact, disclosure to others and making them more aware of the HIV epidemic within their midst could contribute to decreasing the level of stigma within their community (Visser et al., 2008).

The specific social context within which people live materially affects their experience of a chronic illness like HIV/AIDS. Their treatment needs can be shaped by socio-economic factors, the political environment and culturally

mediated ideas about gender, age, sexuality and illness in general. The socio-economic context could even affect access to treatment and whether people experience HIV/AIDS as a long-lasting illness or a terminal one. Often, many of these social factors also affect the nature and strength of stigmatisation of HIV/AIDS. The focus in this section is on how responses to social stigmatisation affect the impact of stigma. It is worth noting that research on stigma and discrimination needs to be part of a broader understanding of people's experiences of and responses to the illness within their ordinary spheres of life (Deacon et al., 2005).

2.5.1 Response to HIV/AIDS Stigma and Discrimination

According to Deacon et al. (2005) most of the disease stigma literature looks closely at the process and functions of stigmatisation from the perspective of the stigmatiser rather than the stigmatised. This is suitable to some extent, given that stigma is initiated by those who stigmatise and perpetuated (to some extent) by entrenched social patterns of exclusion. However, understanding how HIV-positive people experience and respond to stigmatisation is no less important, because the way people respond to stigmatisation is a significant determinant of the impact of stigma. Stigmatised people may, for instance, suffer disadvantage without experiencing any direct discrimination by shying away from situations that they think will be discriminatory. AIDS-related stigma has impacted on the lives of many individuals. Stigma can be internalised and may thus attribute to:

- Withdrawal from society
- Self-doubt
- Lower self-esteem
- Depression
- Harming intimate relationships
- Immuno-suppression
- Even premature death, because it discourages treatment-seeking behaviour (Santana & Dancy, 2000).

The experience of and response to stigma by HIV-positive people thus justify special enquiry to counter the negative effects of the AIDS epidemic. Internalised stigma has often been considered in the literature as a "type" of stigma. Internalisation of stigma or self-stigmatisation involves accepting some of the negative social judgements as part of one's own identity (Deacon et al., 2005).

When others express stigmatising ideologies, HIV-positive people experience the status loss and moral judgements to be projected onto them. This may occur when a person expresses stigma directly to them (direct) or when a person living with HIV/AIDS reads a newspaper in which stigmatising views are expressed (indirect). HIV-positive people may also suffer disadvantage directly or indirectly when discrimination happens. Much of the concern is with the way in which HIV-

positive people act as a result of projecting their direct or indirect experiences of stigmatisation or discrimination into the future (Deacon et al., 2005).

Stigma may not necessarily result in action or discrimination. One would need to investigate stigma and discrimination interrelationships, examining not only “perceived stigma” but also expected discrimination. HIV-positive people may use perceptions of both to plan their actions and many will act on the basis that stigma commonly provides access to discrimination. We sometimes need to research stigma and discrimination as separate concepts, and sometimes we need to investigate their close relationships or how the responses to both could be similar (Deacon et al., 2005).

Miller and Kaiser (2001) suggest that there have been several efforts to distinguish conceptually and empirically among the many different responses people may have to stress. Some of the distinctions that have been suggested as important include distinguishing between voluntary and involuntary responses; emotion-focused and problem-focused coping responses; primary versus secondary control coping efforts; engagement (approach) versus disengagement (avoidance) responses; active and passive coping; cognitive and behavioural coping. The most fundamental distinction between different responses to stress can be made between voluntary coping responses and involuntary responses. This distinction emphasises the fact that not everything a person does in response to stress constitutes coping. People may have involuntary emotional, behavioural, physiological and cognitive responses to stress that do not serve to regulate or modify stressful experiences. These involuntary responses may be conscious or subconscious but they are experienced as being largely outside of the person’s control. People respond to stigma and other stressors in a number of ways, and feedback from one response alters other responses (Miller & Kaiser, 2001). It was also shown in a study that the way HIV-positive women think about HIV-related stressors is an important factor that may account for individual variability in the ability to maintain a sense of subjective well-being in the face of a devastating fatal disease (Moneyham, Seals, Demi, Sowell, Cohen & Guillory, 1996).

Both voluntary coping responses and involuntary responses to stress can involve engagement or disengagement with the stressful event or problem. This distinction is derived from older distinctions between fight (engagement) and flight (disengagement) responses and between approach and avoidance responses. Thus, engagement with a stressor does not necessarily imply conscious, volitional, higher-order cognitive processing (Miller & Kaiser, 2001).

Miller and Kaiser (2001) further indicate that not all responses to stigmatisation are necessarily maladaptive. In fact, they may also represent positive ways of coping with the stressor. It will be shown below how other HIV-positive people have overcome the harmful consequences of stigmatisation. According to Shih

(2004), the following positive responses to stigma are identified, which can be used in therapy simultaneously to assist HIV-infected women to cope.

- Compensation

Miller and Major (2002) mention that stigmatised individuals develop skills to compensate for stigma. These skills assist them to achieve their goals and overcome the disadvantages associated with the stigma. One compensation strategy that stigmatised individuals adopt is to try harder by being more persistent or assertive in paying closer attention about how they present themselves. Dion and Stein (1978) state that researchers found that unattractive female adolescents were more assertive when they tried to influence their peers than were attractive female adolescents. Stigmatised individuals may also try harder to be more likeable.

- Strategic interpretations of the social environment

Stigmatised individuals also strategically manipulate their interpretations of their social environment to protect their sense of self-worth. For instance, they make selective social comparisons. Rather than comparing themselves to individuals from advantaged groups who tend to have better outcomes, stigmatised individuals compare themselves to members of their own group who experience similar or worse outcomes. Seeing that one is doing just as well or even better than the others in similar circumstances increases one's sense of self-efficacy (Shih, 2004).

- Multiple identities help stigmatised individuals to handle prejudice and discrimination

Stigmatised individuals can draw upon their alternate identities to protect themselves from stigma (for example, consider an African, female, Christian attorney, who can simultaneously be identified by her ethnicity, gender, religion, occupation or any combination of these identities). Most work on social identity and stigma focuses on a single identity, usually the stigmatised identity. However, individuals carry multiple identities in the real world (Hewstone, 2000). Thus, while stigmatised individuals can be defined by their stigmatised identities, they can also be defined by a host of other identities. Moreover, it was found (Shih, 2004) that multiple identities protect psychological well-being. Individuals with greater self-complexity had more resilience to handle stress-related illnesses and depression, had more opportunities to gather support and felt greater life satisfaction. These benefits were also found for individuals who possessed identities that were not valued. Identity switching is one process through which multiple identities protect the individual's psychological well-being. Since stigmas are social

constructions, certain identities may be stigmatised in one social context but not in another. Thus, individuals can strategically emphasise identities that are valued and de-emphasise identities that are not valued in any given social context (Shih, 2004).

- The adoption of an “empowerment” model as opposed to a “coping” model when dealing with stigma

Stigmatised people view overcoming the adversities associated with stigma as an empowering process rather than as a depleting process. This discussion underscores the significance of adopting an approach to gain a fuller understanding of the experience of being stigmatised (Shih, 2004).

Researchers propose two models to account for the consequences of adopting these protective strategies and developing resilience. The first responses to stigmatisation may be considered either maladaptive or adaptive, depending on circumstances and on who makes the judgement. Although avoidance-coping mechanisms are usually thought of as maladaptive in the literature, HIV-positive people in a South African study (Stein, 1996) derived benefit from some forms of avoidance coping such as non-disclosure and repudiation of negative ideas about HIV and about their HIV-positive status. These coping mechanisms do not necessarily constitute denial of HIV-positive status, but an endeavour to reject its stigmatising connotations. Stein (1996) is of the opinion that non-disclosure of HIV-positive status may be functional to the HIV-positive person’s privacy and peace of mind, yet it may also be seen as a maladaptive response because it is not an “active” work-through and acceptance of the illness. In the absence of safer sex practises, non-disclosure to sexual partners may also put them at greater risk of contracting the virus.

Deacon et al. (2005) argue that instead of blaming HIV-positive people for failing to respond to stigma, it may be better to focus on finding out what responses people find most useful and why so. We might also direct our attention towards addressing key areas of risk rather than tarring all avoidance-coping mechanisms with the same brush. People react differently to different types of stressors and in different circumstances. Groups of people with a history of stigmatisation sometimes develop common coping mechanisms over a period of time. Deacon et al. (2005) warn that we should also be cautious of describing all behaviour of HIV-positive people in terms of HIV or related stigma. A number of factors influence people’s problems, identities and behaviours, and not just their stigmatised status. HIV-positive people often complain that people assume “the virus” takes over their whole personality.

2.5.2 Internalisation of Stigma or Self-stigmatisation

The researcher will describe self-stigmatisation as a response by HIV-positive people to stigmatisation as suggested by Deacon et al. (2005). Since HIV-positive people generally have some experience or expectation about HIV and how society stigmatises them or perceives them to be, they react by conforming to or resisting this framework. Conforming involves internalisation of stigma or accepting society's negative judgement of one's identity as HIV positive. This is psychologically very damaging because it can reduce the self-esteem of the stigmatised person, which will possibly affect the way he/she responds to the illness, which can reduce the incentive to challenge stigmatisation or discrimination. In addition, this can have undesirable consequences for the individual and the public health programmes, for it possibly reduces self-esteem and discourages being tested for HIV/AIDS, disclosure and the seeking of treatment.

A hidden stigmatised status (concealable stigma) can be very damaging too. Goffman (1963) differentiates between being discreditable (having an attribute that will be stigmatised if it were revealed, but choosing not to disclose it) and being discredited (having a visible stigma, or having disclosed a stigmatising attribute). Hiding or revealing a previously hidden stigma can cause bigger psychological distress than revealing a stigma that has not been, or cannot be hidden. Smart and Wegner (1999) refer to this activity as "passing" and observed that being able to conceal a socially devalued aspect of the self may be viewed by the people with these types of stigmas as highly advantageous in social interactions. It may enable them to minimise the impact that their stigma has on others' judgements of them and to be accepted as "normal". Attempting to influence what is revealed or not revealed about oneself in social interaction, however, demands a great deal of mental control. In the effort to hide something significant about themselves, individuals who have concealable stigmas may face an internal struggle that may have serious costs. People who try to hide their status experience greater anxiety than those who reveal it. This was also shown in a study conducted by Smart and Wegner (1999) about eating disorders of anorexia nervosa and bulimia. The same may be applicable to HIV-positive people.

Having concealable stigma is likely to affect even the types of social relationships in which people with these kinds of stigmas choose to become involved. Hiding the characteristic for which they are stigmatised by others allows them to assimilate into mainstream community life. At the same time, one of the consequences is that they avoid associating with other similarly stigmatised people. In doing so, they deprive themselves of many of the benefits such as the social support, social services and social relationships that come with being open about the stigma. In addition, they are unable to engage in downward social comparison because they are likely to want to avoid others who may have a characteristic for which they are more stigmatised than they are. This is in an

effort to avoid being associated with the stigma and possibly being implicated in processing it (Smart & Wegner, 1999).

Therefore, stigmatisation influences the way people negotiate their own identity and the way they behave, whether or not their HIV status is revealed to others. Self-stigmatisation is generally considered a maladaptive response to stigma by Miller and Kaiser (2001). But if self-stigmatisation is so damaging, the question arises as to why people do it to themselves? Self-stigmatisation is a consequence of repressed anger as a result of being stigmatised. But this is not a useful way of understanding how it happens, as it ignores the social dimension – specifically, the fact that people are socialised prior to self-stigmatisation.

Accepting the stereotypes of the community about a disease may result in internalisation once people acquire that disease. In the absence of alternative frameworks that are publicly supported by society, people may be unable to reconceptualise their status as non-stigmatising. To continue to accept society's definition of deviance may also require that people's sense of belonging within a society be reinforced. If such people "repent" or "reform" they may be accepted once again (Link & Phelan, 2001). In an effort to resist self-stigmatisation, HIV-positive people may deploy an overly positive identity that leaves little room for dealing with illness and psychological distress.

A strong, positive HIV identity has an appeal in South Africa, according to Soskolne, Stein and Gibson (2003), where the widespread nature of the epidemic makes it difficult to limit risk to marginalised outgroups. Because of the nature of the illness, which almost always leads to illness and premature death in the absence of effective treatments, there are difficulties inherent in maintaining a wholly positive view of HIV-positive status that focuses on strength and good health. An HIV-positive identity does not leave space for speaking about psychological distress and sickness associated with the disease or for preparing for the phase of ill-health and later death, even where people do have access to treatment. It can also cause anxiety as HIV-positive people feel they have to appear healthy even when they may not be. It is therefore significant to integrate some of the negative and painful aspects of life with HIV/AIDS within a more nuanced identity for an HIV-positive person.

There are many disorders, behaviours and medical conditions that are potentially stigmatising in this society. A common strategy for those who have these stigmas is to attempt to keep this information about themselves hidden and thus avoid the questions and adjustments of others as much as possible. People who hide their status may be struggling a great deal more than it appears. Although they may escape the immediate damage of negative social behaviour and evaluation, they may bring the conflict into their own minds, as it were, and thus become pre-occupied with covering up what no one can see (Smart & Wegner, 1999).

2.5.3 Expected Stigmatisation and Discrimination

Perceived or expected stigma and discrimination is the second issue concerning HIV-positive people's responses to stigma. Stigmatised people can directly experience stigma and discrimination if their status is known, but their perceptions of stigma are influenced by how they identify themselves (as members of a stigmatised group) and how they perceive others (as stigmatising). Their level of exposure to stigma and discrimination and what they have already experienced, read about or heard of, can affect their perception of how much it is going to affect them in the future.

The levels of expected stigmatisation and discrimination can materially affect the self-esteem and behaviour of HIV-positive people. The individuals' perceptions of stigma account for the important differences seen in the impact of an illness on the self. Higher perceived stigma reduced the probability of disclosure of HIV-positive status in African-American women in the United States (US). Lichtenstein (2003) shows that perceived levels of stigma may also have a negative effect on willingness to go for voluntary counselling and testing (VCT) and treatment.

It is indicated by some research that levels of stigma perceived by HIV-positive people tend to be higher than "actual" levels of stigma. Green (1995) found that HIV-positive people generally had more liberal attitudes towards HIV-positive people than the general public, but felt that attitudes towards them were far less liberal than stated by the general public. Visser and Makin (2004) suggest that perceived stigma played a bigger role in determining HIV-positive women's experience of community stigma than did enacted stigma or community support.

Shisana and Simbayi (2002) are of the opinion that it is dangerous to assume that there is necessarily less stigma and discrimination in the general public than HIV-positive people think, because it is very difficult to measure the amount of probable stigma and discrimination in the public sphere. The mismatch between perceived and reported stigma could instead suggest that the general public under-report stigma against HIV-positive people, a factor that could explain the very low reported levels of stigma in the Nelson Mandela/Human Sciences Research Council (HSRC) study.

One needs to examine the situation from the perspective of HIV-positive people, instead of concentrating only on the negative impact of high levels of expected stigmatisation and discrimination on necessary public health goals (e.g. persuading members of the public to go for VCT and treatment and disclosing their status). HIV-positive people might, for example, choose to hide their status to avoid discrimination – simply asking people to disclose, without offering extra support or an effective barrier to discrimination, will not remove this disincentive. In their attempt to focus on the experience of stigma by stigmatised people, researchers need to be careful not to use research to assign fault to stigmatised

people for seeing stigma and discrimination that does not really exist, or to patronise HIV-positive people for not confronting it, such as through disclosure of HIV status. HIV-positive people can also be assisted in selectively disclosing to people that can support them in order to prevent further HIV transmission, although the difficulty in doing so because of potential stigmatisation is acknowledged.

The impact of stigmatisation cannot be understood by measuring what supposedly HIV-negative people say they think about HIV-positive people or how they intend to act towards them, because HIV-positive people respond to stigma and discrimination based not only on their own experiences, but also on what they encounter in the media and hear from other people. Expected stigmatisation and discrimination could be an even greater barrier to those living with HIV in accessing treatment and support than levels of reported or actual stigma or discrimination might suggest. Expected stigma and discrimination is thus a significant but under-researched area (Deacon et al., 2005). The following section will deal firstly with categorising differential treatment and secondly with differential treatment versus discrimination.

2.6 INTERVENTIONS TO ADDRESS STIGMA AND DISCRIMINATION

Discrimination is the basis for most of people's concerns about stigma. In this section, the researcher differentiates between positive and protective kinds of differential treatment on the one hand and unfair discrimination on the other. Because of the conflation of stigma and discrimination, existing research measures intended discrimination – what people mention they will do – as an index of stigma. All unfair discrimination against HIV-positive people is commonly associated with stigma. It is important to avoid defining stigma in terms of discrimination, or discrimination in terms of stigma, because discrimination is not always caused by stigma and is not a good measure of the impact of stigma. Stigmatisation may have negative effects (increasing expected stigmatisation and discrimination) without actually resulting in discrimination. In an attempt to combat the effects of stigma, one should differentiate between situations in which stigma directly causes discrimination and situations in which discrimination is caused by other factors such as sexism, racism or resource concerns. In doing research about discrimination, one needs to find out more about why people intend to discriminate and how intended discrimination relates to action (Deacon et al., 2005).

2.6.1 Categorising Differential Treatment

Differential treatment can be categorised under four aims, according to Deacon et al. (2005): redress, prevention of infection, social distancing and the balancing of social contributions.

2.6.1.1 Redress

Redress refers to situations where disadvantages have been conferred on a group of people by physical differences or cultural prejudice, and societies feel the obligation of redress, as it would be described below. For example, in the race, gender and disability fields, the existence of historical discrimination and the effects of physical differences have on occasion been addressed deliberately. This has been addressed by employment equity programmes, by providing women with guaranteed maternity leave or by providing separate track and field events for those athletes with physical disabilities. HIV-positive people or disabled people may on other occasions receive disability benefits to offset loss of income or to meet specific additional needs. The main problem with providing disability grants on the basis of illness is that, in an environment of grinding poverty and high unemployment such as our country, it provides a perverse incentive to stay sick and possibly even to get sick in order to benefit from the grants (Nattrass, 2004). Such a choice could result in many people shifting between disability grants and AIDS treatment, with the result that the treatment regimen will be a lot less effective and more conducive to drug resistance (Boule, 2003).

2.6.1.2 Preventing Infection

Some kinds of differential treatment for HIV-positive people (rejection of their blood products for transfusions) are validated by medical science while others are invalidated (refusal to shake hands with or hug HIV-positive people). Ignorance of scientifically validated modes of spreading HIV may result in unfair discrimination. Even if strategies are likely to be effective, measures to prevent infection have to be balanced against other factors such as cost and human rights issues. For instance, asking patients' HIV status before a major operation may enable medical staff to be protected against the virus and it may be effective for them. However, this might constitute the violation of HIV-positive persons' rights, especially if they are unwilling to be tested.

2.6.1.3 Social Distancing

Social distancing occurs in cases where HIV-positive people are judged to be promiscuous or immoral. Social distancing is also related to fear of casual transmission. HIV-positive people may experience varying kinds and degrees of status loss and discrimination. For instance, they may be excluded from a religious community. Such a form of discrimination is a direct consequence of stigmatisation, which assists to affirm risk-free identities by projecting negatively defined characteristics and risky behaviours onto other groups.

2.6.1.4 Balancing Social Contributions

Other kinds of discrimination – for instance loss of the right to medical aid, pension, life insurance benefits and education – have been based on lower expected contributions to society by HIV-positive people and higher expected burdens on the family or the public purse. Because of its violation of the human rights of HIV-positive people, such discrimination has been challenged.

2.6.2 Differential Treatment versus Discrimination

Given the long history of using biological differences based on race, gender and disability to justify unfair discrimination, one should be cautious when determining what differential treatment is actually warranted by the threat of infection. Discrimination that is aimed at preventing infection is sometimes based not on actual risk of HIV infection, but on incorrect scientific knowledge or on an overestimation of the potential risk. For instance, HIV-positive patients in US hospitals were at first treated as though the condition was highly infectious, and some people still think that HIV can be spread through ordinary social contact such as touching, hugging, sharing eating implements and using same bathrooms - this is known as an “instrumental stigma” (Herek, 2002).

In an endeavour to understand whether differential treatment is discriminatory (fair or unfair), one has to recognise that there is a difference between judging public health discourses and related public health measures on the one hand, and judging individual discourses and actions on the other. In the personal sphere it is acceptable to make personal choices to meet personal needs and reduce personal risk. Few public health professionals would consider it to be unfair discrimination if an individual were to refuse to have sex with a person openly living with HIV/AIDS (with or without a condom) because he/she wishes to avoid any risk of contracting the virus or, indeed, wishes to avoid increasing his/her own viral load if he/she is also HIV-positive. In the presence of other STDs, the same would be true regarding individual sexual decision making. Unfair discrimination would involve unnecessary measures to reduce risk (for example, refusing to shake hands or hugging) or moral judgements (such as claiming that a person contracted HIV because he/she was promiscuous). The rejection of HIV/AIDS stigma is based on the understanding that all acts of social exclusion relating to HIV/AIDS are not only morally wrong but also counterproductive to effective HIV/AIDS prevention and treatment (Stein, 2003).

On the other hand, public health strategies against the spread of the HIV/AIDS pandemic generally avoid singling out HIV-positive people because this would further stigmatise them, contravene their human rights, and discourage public co-operation, VCT and disclosure. Equality of treatment is a crucial gauge of the acceptability of public health measures in the public health context, even where these are designed to reduce the chances of some people infecting others (Deacon et al., 2005).

Differential treatment may have adverse consequences within a stigmatising society even if it is aimed at redress or the prevention of infection. The difficulty with current public health programmes in relation to stigma and discrimination is not that they single out HIV-positive people for special treatment. In fact, the problem is that guidance on how to remain HIV negative (for instance, abstaining, being faithful) seems to support the stigmatising notion that people who have HIV are promiscuous. It is, however, true that the more sexual partners' people have, the more likely they are to contract HIV from someone (epidemiological risk). It is equally true that HIV can be contracted from a single sexual encounter with an HIV-positive person, even if that person happens to be one's only sexual partner (individual risk). HIV is not caused by promiscuity – it simply happens to be transmitted sexually, as well as in other ways such as HIV-infected blood being passed directly into the body (blood transfusion) and from mother to child during pregnancy, childbirth and breast-feeding (De Cock, 1996; Evian, 2003; Hubley, 2002; Klatt, 2005; Whelan, 2002).

Skinner (2002) expresses the view that the promotion of condom use as a means to combat the spread of HIV infection has also assisted, paradoxically, to stigmatise condom use (“people who use condoms are people who have slept around or who think their partner has slept around”). Where public health measures do single out HIV-positive people for special services (for instance, special ARV clinics, provision of formula feeds for HIV-positive mothers or the provision of certain medicines), these often become markers of HIV-positive status and are stigmatised – called secondary stigmatisation.

In understanding the impact of stigma, Deacon et al. (2005) recommend that one needs to conduct research not only on unfair discrimination and on HIV-positive people's perceptions of stigma and discrimination, but also on the unintended consequences of legitimate forms of differential treatment in public health programmes and campaigns.

In researching discrimination about what forms of differential treatment constitute discrimination, one needs to be clear about why they are unfair and whether, in specific cases, they are caused by stigma or other factors. HIV/AIDS activists and other people have assisted to expand the notion of discrimination to include transgressions of the human rights of HIV-positive people. This would, for instance, include refusal of employment to an HIV-positive person on the grounds that an HIV-positive person is likely to die sooner than an HIV-negative person. Such an example would not only be unfair because it transgresses the human rights of an HIV-positive person, it would also be unfair because other diseases such as cancer are less easily detected in their early stages and may be equally dangerous to someone's career.

Human rights issues raise an interesting question concerning the role of the household in sustaining a person living with HIV/AIDS. For example, decision makers in households make triage-like calculations about how likely a sick



household member is to recover and how much it is costing to treat and feed him/her relative to household income. It would be detrimental to mention that such discrimination would be legitimate, since the household is supposed to be the one place where people are being unconditionally cared for. Discrimination of this kind (for example, the withholding of food) happens quite frequently, especially in resource-poor situations where even free treatment is too expensive or difficult to access. The financial benefit of receiving a disability grant while a sick person is alive is weighed against the cost of special food for the invalid and the potential income from life insurance or funeral benefits on death.

This section has focused on internalisation of stigma, expected stigma and discrimination. Discrimination in this chapter has been indicated to be a significant area of investigation that has been under-researched because of the conflation of stigma and discrimination in the literature and the use of survey data on intended discrimination as a measure of both. Four main categories of differential treatment have been discussed and all these forms of differential treatment are worthy of investigation – both to assist the general public to differentiate between fair and unfair differential treatment, and to understand the potentially negative impact of certain well-meaning public health programmes and campaigns within a stigmatising society (Deacon et al., 2005).

In the next chapter the researcher focuses on the theoretical perspectives on how to facilitate change through psychotherapy, and especially on how to help women to change their experience of and reaction to stigma.