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**THE PERCEPTIONS AND EXPERIENCES OF A SAMPLE  
OF WOMEN, LIVING IN KHAYELITSHA, AFTER  
RECEIVING AN HIV-POSITIVE DIAGNOSIS**

Marina Adelaide Solomon

Student Number: SLMMAR004

Supervisor: Mrs. S. Sturgeon

A minor dissertation in accordance with the requirements for the award of the  
Degree of Masters in Clinical Social Work

Faculty of Social Development

University of Cape Town

2006

## **DECLARATION**

This work has not previously been submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

Signature: .....

Date: .....

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## **ACKNOWLEDGEMENTS**

Grateful thanks to the following:

The volunteer leader, facilitators and group members of the HIV/AIDS clinic in Khayelitsha who allowed me access to their support groups and who willingly shared their stories with me.

My supervisor, Shona Sturgeon, for her support and assistance, not only technically but also emotionally.

Vivian Taylor, for her belief in me.

Kathy Collins, for starting out on this journey with me.

Lily Becker, for her support.

Sharman Wickham, for her guidance and support.

The Department of Social Development Staff, for their support, encouragement and input.

Above all, thanks to my entire family, especially my husband, Alan, and my children, Lore, Wayde and Craig, for their encouragement, support and belief in me.

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## ABSTRACT

This study explores the perceptions and experiences of 20 women, living in Khayelitsha and currently attending an HIV/AIDS support group in the area, after receiving an HIV-positive diagnosis. The study considers their available resources such as knowledge of the disease and financial means. The issue of stigma and how this impacts on their daily lives is also examined. Finally, the effects of joining an HIV/AIDS support group are explored.

The study utilises a qualitative approach which is exploratory and descriptive in nature and is conducted from within a non-probability framework. Thematic content analysis is used to classify the qualitative data collected by means of interviews. The conclusions reached from this study are that receiving an HIV-positive diagnosis is often construed as a death sentence by women who have limited factual knowledge regarding HIV/AIDS. What they have learned from the mass media, their family, friends and community members leads them to believe that they have no control over their fate once diagnosed as HIV-positive. Consequently, they experience feelings of helplessness, anxiety and depression and this impedes the initiation of appropriate positive responses. In addition, a lack of financial resources and stigma suffered or the fear thereof further impact on their ability to react optimally to such a diagnosis.

This study also shows that education, support and acceptance received whilst attending an HIV/AIDS support group has proved beneficial for all of these women. Key recommendations arising out of the findings include particular circumstances in which the communication of an HIV-positive diagnosis takes place and the means by which educational institutions, businesses, government and the media can contribute to a greater understanding of and destigmatization of HIV/AIDS. In conclusion, support group programmes and activities are recommended to foster increased self-esteem, greater self-sufficiency and a sense of empowerment.

# **CHAPTER 1 INTRODUCTION TO THE STUDY**

## **1.1. INTRODUCTION TO THE CHAPTER**

This chapter introduces the problem statement followed by the clarification of the concepts HIV and AIDS and the background to the research problem. The latter includes a brief discussion of the HIV/AIDS pandemic, its presence in Africa and South Africa and its significance for women as well as the social and cultural meanings of HIV/AIDS, the progression of HIV/AIDS through its four stages and the means to combat this progression, which includes ARV treatment. The topic, context, rationale and significance of this study are outlined, the main questions and the objectives are detailed and, in conclusion, the structure of this report is described.

## **1.2. THE PROBLEM STATEMENT**

HIV/AIDS is a highly stigmatized disease which at present in South Africa affects more women than men. Women in black townships are particularly vulnerable as a result of poverty and societal institutions which impact on their ability to negotiate safe sexual practices. "Women are often infected at ages up to ten years younger than men, and frequently have a poorer prognosis, and die sooner" (Soskolne, 2003:2). HIV/AIDS is therefore a critical problem for women: how they react to and live with an HIV-positive diagnosis has important consequences for their welfare and quality of life.

## **1.3. CLARIFICATION OF HIV/AIDS**

In order to clarify the important terms used in this study, the concepts of HIV and AIDS are explained below.

### **1.3.1. HIV**

HIV (Human Immunodeficiency Virus), the virus which causes AIDS, is a retrovirus which enters a cell and inserts itself into the cell's DNA to reproduce itself.

Once the HI virus enters the body, it attacks the CD4 cells which organise the body's immune response to foreign bodies and infections and also the immune cells called macrophages, which leads to a gradual weakening of the immune system, making it impossible for the body to fight infections (A World Bank Policy Research Report, 1999; Mbuya, 2000; Whiteside & Sunter, 2000; Usdin, 2003; Mombe, 2004).

Usdin (2003:68) writes: "If HIV was a person, it would be a nasty piece of work. Sneaky in many ways, it seems built for surviving today's mean streets. Although fragile and unable to live for long periods outside the human body, the virus can insinuate itself into human cells and replicate at a phenomenal rate. While effective medicines exist to slow it down, it is cunning and can mutate, so far surviving all attempts to annihilate it."

HIV may enter the body by means of:

- (i) sexual transmission (signifying the vast majority of HIV infections);
- (ii) transmission from pregnant mother to child, either pre-natally or at birth, but not all HIV-positive mothers give birth to babies who are HIV-positive and antiretroviral treatment can greatly reduce the chances of transmission. This is the second most important cause of HIV infection in South Africa;
- (iii) breast feeding, if the mother is HIV-positive;
- (iv) intravenous drug use with contaminated needles (drug users who share needles are at risk of infection);
- (v) the use of infected blood or blood products (blood transfusions);
- (vi) other methods, such as:
  - contaminated medical or other instruments eg. dental equipment, syringes and tattoo needles;
  - accidents through needle-stick injury or surgery;
  - bodily contact involving open bleeding wounds (eg. in sport or during first aid procedures).

HIV is not transmitted via the body fluids such as sweat, tears, saliva, urine, faeces and vomit, as it is not found in sufficient quantities in these substances. Blood, breast milk, vaginal secretions or semen have to be involved.

Thus, HIV is not spread through casual contact and the sharing of eating utensils or toilets. HIV is also not transmitted by insect bites such as those of mosquitoes or bedbugs (A World Bank Policy Research Report, 1999; Mbuya, 2000; Whiteside & Sunter, 2000; Holden, 2003; Cochrane, 2004).

### **1.3.2. AIDS**

AIDS (Acquired Immunodeficiency Syndrome) is acquired, leads to an immune deficiency and is a syndrome, consisting of many different symptoms, diseases and problems which arise as the immune system becomes deficient. AIDS is caused by HIV (Human Immunodeficiency Virus) and is the final stage of HIV infection when the body, whose immune system has been destroyed by the HI virus, can no longer fight infections (Frankenberg, 1987; Dossier, 1989; A World Bank Policy Research Report, 1999; Mbuya, 2000; Whiteside & Sunter, 2000; Usdin, 2003).

## **1.4. BACKGROUND TO THE RESEARCH PROBLEM**

### **1.4.1. The HIV/AIDS Pandemic**

HIV/AIDS is an epidemic of global proportions. At a November 2002 Washington dinner, the U.S. Secretary of State, Colin Powell (as cited in Hunter, 2003:8) surprised the guests when he declared that the most serious problem facing the world today is not terrorism, but the HIV/AIDS epidemic. "AIDS is not a future threat, it is destabilizing our entire planet right now and will have far worse consequences than any event a terrorist could ever invent." The seriousness of this statement is echoed by A.Veneman, the executive director of Unicef, who is quoted in the *Mail & Guardian* (2005:30) as saying that: "In the past quarter of a century, HIV/AIDS has claimed the lives of more than 20 million people and lowered life expectancy in the hardest-hit countries by as much as 30 years." The estimated total worldwide HIV infections as at 26 October 2005 were 64 877 123 (Mail & Guardian, 2005:31) and Mombe (2004:29) writes: "Continuously advancing in some parts of the world, AIDS today constitutes one of the most devastating scourges humankind has ever faced."

### **1.4.2. HIV/AIDS in Africa**

Sub-Saharan Africa is presently the epicentre of HIV and AIDS and 70% of the world's HIV infected people live in this region, which houses 10% of the global population. In addition, around 90% of infected infants and children reside here (Whiteside & Sunter, 2000; Sachs & Sachs, 2004). Sonia and Jeffrey Sachs (2003:9) state the statistics quite clearly: "We have until today had around 65 million people infected, 25 million of whom have already died, and 40 million living with the virus, of whom 30 million are in Africa." UNAIDS estimates that "55 million additional deaths will occur in the next 20 years" in sub-Saharan Africa (Usdin, 2003:30). Nelson Mandela, former President of South Africa, as cited in Usdin (2003:25) stated: "Let us not equivocate. AIDS today in Africa is claiming more lives than the sum total of all wars, famines and floods, and the ravages of such deadly diseases as malaria. It is devastating families and communities."

The US Bureau of the Census has projected that by 2010, HIV/AIDS will decrease life expectancy by approximately 20% in the worst affected African countries and the World Bank has estimated that life expectancy in sub-Saharan Africa will be 43 by 2020 because of AIDS, against 62 without AIDS (Fransen, 1998; Loewenson & Whiteside, 1998).

### **1.4.3. HIV/AIDS in South Africa**

Archbishop Desmond M. Tutu wrote: "In the early 1980s the international medical community was only starting to understand this dangerous new disease and here in South Africa it was something we were totally unaware of" (Kauffman & Lindauer, 2003:xi). However, by 1998 UNAIDS issued a map showing global infections and the caption read: "No place on earth untouched" (Whiteside & Sunter, 2000:36). Unfortunately, some places, including South Africa, are touched more than others.

Regarding the situation in South Africa, Archbishop Desmond M. Tutu in July 2003 said in his foreword to the publication 'AIDS and South Africa: the Social Expression of a Pandemic': "We have over 5 million citizens who are HIV-positive. We already have lost well over a million of our brothers and sisters to AIDS."

“We have over 600 000 AIDS orphans. And the end of this plague is still not in sight, the worst still lies ahead of us” (Kauffman & Lindauer, 2004:xi). This sentiment is echoed by E. Naidu (2006:10) who reports that according to a new government progress report on HIV/AIDS, “Despite increased spending by the public and private sector on HIV/AIDS awareness programmes, more people are getting infected.”

Kauffman (2004:17) asks the question: “Why is South Africa the HIV Capital of the World?” In reply it could be said that the HI virus is said to seek out populations “made doubly vulnerable by their lack of information, and by their health, behavioural and socio-economic status” (Dossier, 1989:iii). South Africa has the second highest number of HIV-positive people of any nation and had “the highest number of HIV/AIDS deaths in the world last year” (Thom, 2006:10). The *Mail & Guardian* reported that as at noon on 30 November 2005, the estimated AIDS-related deaths in South Africa stood at a total of 1 628 887 (2005:27).

HIV/AIDS, which could not have been found in any medical dictionary only 25 years ago, has today become one of the most serious problems facing southern Africa. Not only is it a public health burden in itself, but it is also directly linked to other significant public health problems. HIV interacts with other diseases and STD's increase the rate of HIV transmission tenfold. Furthermore, there are also significant increases in tuberculosis cases which are directly related to HIV (Loewenson & Whiteside, 1998). Smith & Caelers (2005:3) write that “A staggering two-thirds of all tuberculosis patients in Cape Town are HIV-positive.”

Although we now know how the virus is spread, how infection can be prevented and which treatment slows the progression of the disease, infection still continues at an alarming rate on the African continent. Lindauer (2004:176) writes that “Every twenty-four hours it is estimated that over 2000 South Africans will be infected with the HI virus.”

If AIDS continues unabated, more young and middle aged productive adults as well as trained and skilled individuals will die, infant mortality will rise and many children will be orphaned. This is the reality of the epidemic.

We are now in the third decade of this epidemic and millions of people worldwide have become infected. Evidence suggests that once AIDS develops it is always fatal, as the cure for AIDS seems as elusive now as it was when the epidemic began. Similarly, there is still no vaccine against HIV that can provide immunity for populations at risk for the disease (Dossier, 1989; Cochrane, 2004).

“Until a cure is found, most people who are already infected are likely at some stage to develop AIDS related diseases from which they will die” (Mbuya, 2000:107). Hunter (2003:7) claims that in the next 10 to 15 years, AIDS will claim more lives than any other human epidemic ever recorded and that by 2010, the death toll will be higher than that of both world wars - “it will soon be worse than the total claimed by all wars put together”. She says that there is nothing to compare it to, ..”no scale of human suffering and devastation against which this terrible plague can possibly be measured” (Hunter, 2003:7). Dr. Makgoba, the former head of South Africa’s Medical Research Council, said that only a war could result in comparable deaths among young people (Hunter, 2003). He further warned that “if the epidemic went unchecked, it would claim between five and seven million South Africans by 2010.” (as cited in van der Vliet, 2004:67).

#### **1.4.4. Women and HIV/AIDS**

Although AIDS first came to the public’s attention on the 5<sup>th</sup> June 1981 as a “gay-related immune deficiency”, spread by homosexual males, the number of HIV-positive women is increasing and in most of Africa heterosexual transmission is dominant and more women than men are infected (Whiteside & Sunter, 2000; Cochrane, 2004). Mombe (2004) writes that in Sub-Saharan Africa, 58% of HIV infected individuals are females. The 2004 South African National HIV and Syphilis Antenatal Seroprevalence Survey found that in South Africa, too, the number of HIV-positive women outstrips that of men. Estimates indicate that there are 3.3 million HIV-positive women and 2.8 million HIV-positive men in South Africa (Caelers, 2005). Witbooi and du Plessis (2006:1) write that statistics released by Statistics South Africa show that deaths of women aged between 20 and 39 have trebled between 1997 and 2004 and “the main cause appears to be infectious diseases that are linked to HIV/AIDS.”

It has been found that women are infected at a younger age than men and Fransen (1998) points out that recent data indicates that up to 60% of all new HIV infections are among 15-24 year olds with females outnumbering males by a ratio of two to one. Various factors contribute to a woman's risk of contracting HIV/AIDS. Factors that seem to influence levels of HIV/AIDS prevalence are those related to poverty, inequity, gender imbalances, circumcision practices and the level of sexually transmitted diseases (STDs). Both formal and informal institutions have an important impact on society and governmental ambivalence regarding HIV/AIDS and its treatment, together with societal norms regarding male and female roles play an integral part in affecting the woman's ability to protect herself against infection (Fransen, 1998; Kauffman & Lindauer, 2004; Poku, 2005).

Many South African mothers only discover their HIV status when they attend an antenatal clinic because of their pregnancy or when their baby develops AIDS related diseases. Between 25% to 50% of HIV-positive mothers pass the virus to their babies before or during birth and many of these babies develop AIDS and die within a few years of their birth (Mbuya, 2000). The impact of HIV/AIDS is that the structure of the population will change, as the number of 20-40 year olds, especially women, will decrease and the number of orphaned children will grow (Lowenson & Whiteside, 1998).

#### **1.4.5. The Social and Cultural Meanings of HIV/AIDS**

The experience of living with HIV/AIDS cannot be separated from the social construction and, therefore, the social and cultural meanings related to this disease. "HIV/AIDS is a phenomenon with frightening social and cultural meaning" (Osei-Hwedie & Osei-Hwedie, 1999:121) and it affects the way in which people live their lives after receiving an HIV-positive diagnosis. Informal institutions dictate who is shunned by society and stigmatized: Sontag (1991:101) avers that AIDS is a highly stigmatised disease and "its capacity to create spoiled identity" is far greater than any other disease. "The ways in which the phenomenon of AIDS has been represented in the entertainment and news mass media have played an important role in the development of shared cultural meanings about AIDS" (Lupton, 1994:9).

The death experience according to the communication by language and vividly described in many publications and portrayed in videos such as “*Angels in America*” and the movie “*Philadelphia*” which show the ravages of this disease, is fear-inducing. *Time International* (2000) wrote of AIDS in South Africa as being “worse than a disaster” and *Time* (2001) called AIDS “humanity’s deadliest cataclysm” (cited in Philips, 2004:31). The messages received from the mass media is thus often that of a fatalistic and ‘death voyeuristic’ nature, suggesting themes of helplessness, rather than being informative and positive about the future.

At present there is no cure for AIDS and therefore an HIV-positive diagnosis could be construed as tantamount to a death sentence. Newspaper headlines such as “Huge rise in AIDS deaths in SA, says TAC” (Caelers, 2005:5) reinforce this fearful knowledge. There are also many other negative aspects concerning such a diagnosis. Social stigma can lead to ostracism and loss of employment and also loss of accommodation and alienation from family, partners and friends. “HIV/AIDS is fast becoming the worst human disease disaster the world has ever seen”, proclaims Hunter (2003:7). Thus AIDS has generated a great deal of fear, loathing and prejudice (Lupton, 1994).

In 1985, after a blood test for detecting HIV antibodies became available, it was no longer necessary to be clinically ill to be considered at risk for developing AIDS, as asymptomatic individuals testing positive for antibodies to the virus became HIV-positive patients. “Sadly, however, the development of the HIV antibody test neither assuaged patients’ suffering nor offered a treatment or a change in prognosis; to the contrary, it only furthered the medicalization of many additional persons, asymptomatic yet HIV-positive, who were now seen as having begun the long descent into sickness and death” (Cochrane, 2004:15). Thus, asymptomatic HIV-positive persons who could be healthy for as many as twenty years, become pathologised and stigmatised.

#### **1.4.6. The Progression of HIV/AIDS**

Currently there is no cure for HIV/AIDS but there is a disparity in the time taken for this disease to evolve from Stage 1 to reach its final phase, Stage 4. This ranges from as few as four years in developing countries to as many as twenty years in industrialised nations.

Although treatment with antiretroviral therapies can prolong the lifespan, aspects concerning the person and the context in which he/she lives also impact on this time factor.

#### 1.4.6.1. The Four Stages of HIV/AIDS

The World Health Organization (WHO) identifies, as described below, the four stages in the progression from HIV infection to AIDS (Usdin, 2003).

##### 1.4.6.1.1. Stage 1

Once an individual is infected with HIV, antibodies are produced by the body to fight the infection and after a 'window period', lasting from three weeks to three months, a test can detect these antibodies and the person is diagnosed as being HIV-positive. This is a very infectious stage and the person often has 'flu' like symptoms.

##### 1.4.6.1.2. Stage 2

The second stage is the asymptomatic period when people, although they are infectious, have no symptoms of HIV infection with the exception perhaps of swollen glands. However, even though there are no symptoms, the HI virus is attacking and weakening the immune system. A healthy individual has up to 1200 CD4 cells per microlitre of blood but progression of the infection drastically reduces the number of CD4 cells.

##### 1.4.6.1.3. Stage 3

The third stage of the disease is when the HIV's damage to the immune system enables opportunistic infections and cancers, which are seldom seen in persons with normal immune systems, to invade the body. This is the symptomatic HIV infection stage and at first these opportunistic diseases may be treatable but they are likely to reoccur.

In Africa, TB is the most common opportunistic infection in people who are HIV-positive and in many parts of Africa “TB is the most common cause of death among people with AIDS” (Usdin, 2003:79).

Once the immune system has been destroyed, infectious organisms can invade the body at will and cause serious diseases. Fungal, parasitic, bacterial and viral infections and malignancies often lead to shingles, tuberculosis, thrush, meningitis and pneumonia. Cancers, especially those caused by viruses such as Kaposi’s sarcoma, cervical cancer and cancers of the immune system, are also often encountered. Further symptoms are loss of short-term memory, mood changes, encephalitis and severe mental disturbance. The person may have times of comparative health between bouts of ill-health (Mbuya, 2000; Whiteside & Sunter, 2000; Holden, 2003; Usdin, 2003).

#### *1.4.6.1.4. Stage 4*

The fourth phase is seen as the final step in the progression to AIDS, which can be determined by a blood test which evaluates the state of the immune system. Evidence shows that the fourth stage of HIV/AIDS ends with death and although most HIV-positive persons will eventually develop AIDS related diseases, it is possible that some may not (Mbuya, 2000). This death is not caused by HIV itself, but by one or more of the diseases which are collectively known as AIDS (Holden,2003).

#### **1.4.7. Means to combat the progression of HIV/AIDS**

The content and context of one’s life impacts greatly on the progression of this disease. People who are poor and do not have proper nourishment and those who suffer from stress, are overworked and who have parasitic diseases which have already weakened the immune system, progress more quickly through the stages than those who are healthy and well fed (Whiteside & Sunter, 2000; Stillwaggon, 2002). There is at present no cure for HIV/AIDS, but there are regimes to adopt which may prolong the asymptomatic, as well as the final phases of the disease and by these means, one can maintain a measure of control over the infection.

These are:

- eating food high in nutritional value;
- practising good hygiene;
- exercising regularly;
- getting sufficient sleep and rest;
- avoiding smoking and alcohol;
- avoiding any addictive substances;
- avoiding unprotected sex;
- attending support groups;
- maintaining a positive attitude;
- attending counselling sessions if possible;
- practising stress-management;
- keeping free of other diseases which also weaken the immune system;
- treating opportunistic infections timeously; and
- complying with Antiretroviral (ARV) medication when it becomes necessary (Usdin,2003; Tulleken, 2005).

#### 1.4.7.1. ARV Treatment

Highly active antiretroviral therapy (HAART) was introduced at the X1 International Conference on AIDS in Vancouver in 1996. This has led to a dramatic drop in AIDS mortality rates and improved quality of life for people living with AIDS (Irwin, Millen & Fellows, 2003:59). “In what became referred to as the ‘Lazarus effect’, “people at death’s door literally came back to life” (Usdin, 2003:24). Mombe (2004:30) writes that HIV/AIDS related illness and mortality has declined more than 50% in industrialized countries due largely to this treatment.

This antiretroviral treatment has “transformed HIV/AIDS from a fatal illness into a manageable disease” (Usdin, 2003:87). However, although the cost of antiretrovirals (ARVs) has decreased considerably, many patients in developing countries are still not receiving treatment and this is seen as the result of “the inadequacy of global AIDS funding and the weakness of many developing countries’ health care systems” (Irwin, Millen & Fallows, 2003:60).

The World Health Organization officially announced the '3 by 5' initiative on December 1, 2003, which was to provide antiretroviral treatment for 3 million people from poor countries by the year 2005 (Mombe, 2004). However, this goal was not achieved.

In South Africa, if one does not have access to private health care, ARV treatment is only available to individuals with a CD4 cell count of below 200. These ARVs cannot cure AIDS but they do afford the immune system an opportunity to recover and resume its work, by preventing HIV from reproducing inside the body, thus lowering the viral load and lessening the likelihood as well as the severity of opportunistic infections (Whiteside & Sunter, 2000; Holden, 2003; Usdin, 2003; Tulleken, 2005). However, the Actuarial Society of South Africa has estimated that there are 537 759 people in our country in need of treatment this year, but according to reports, less than 200 000 individuals were receiving ARV's (Caelers, 2006:3). Furthermore, S.A. Health Minister, Dr. Manto Tshabalala-Msimang, has said that people should decide for themselves whether they prefer antiretroviral treatment, which is toxic, or alternative means, where she recommends beetroot, lemon, garlic and African potatoes (Caelers, 2005). It is possible that these ambiguous governmental messages could have created confusion among the populace who, because of these arguments, may decide to refrain from seeking medical treatment.

Tulleken (2005:28) claims that "By living positively it is possible to lead a healthy and normal life." Added to this, the prevention of and early detection and treatment of opportunistic infections and ARV treatment has improved the quality of life for many HIV-positive individuals (Mombe, 2004). Articles written for the weekly 'Everyone knows someone' column in the *Sunday Times* attest to this fact (Patient, 2006; Mapongwana, 2006). Therefore, how people manage and live with a positive diagnosis of HIV may have far-reaching implications for their quality and length of life.

## **1.5. THE TOPIC OF THIS STUDY**

This study examines the perceptions and experiences of a sample of women, living in Khayelitsha, who have been diagnosed HIV-positive and how the support systems which they utilise are beneficial for them.

## **1.6. THE CONTEXT OF THIS STUDY**

This study was conducted within the geographical confines of Khayelitsha, a township in the Western Cape. Soskolne (2003:9) writes that “Black women, living in township areas, are one of the most marginalised groups in South Africa.” Shabodien (2003) says that Khayelitsha is the township with the highest prevalence of both poverty and HIV in the Western Cape. “HIV/AIDS is a very tangible threat in their community where poverty is endemic and sickness an unsustainable financial and emotional burden” (Soskolne, Stein & Gibson, 2003:5).

## **1.7. MAIN RESEARCH QUESTIONS**

In this study, the main questions explored were:

- 1.7.1. How do a sample of women, who live in Khayelitsha, react and behave after they have been diagnosed HIV-positive?
- 1.7.2. What knowledge do these HIV-positively diagnosed women have regarding HIV/AIDS?
- 1.7.3. Is stigmatization a problem for this sample of women who have been diagnosed HIV-positive?
- 1.7.4. Do these HIV-positively diagnosed women have the necessary financial resources to live an optimally healthy lifestyle?
- 1.7.5. Are the support systems used by these HIV-positively diagnosed women of benefit to them?

## **1.8. THE OBJECTIVES**

Following on from these main questions, the objectives were:

- 1.8.1. To establish how the sample of women, who live in Khayelitsha reacted and managed their lives after receiving an HIV-positive diagnosis.
- 1.8.2. To determine the extent of the women’s knowledge regarding HIV/AIDS and how this influenced their reactions after being diagnosed as HIV-positive.

- 1.8.3. To describe the effect of stigma on HIV-positive women.
- 1.8.4. To explore the financial situation of HIV-positive women which could either facilitate or militate against their leading optimally healthy lifestyles.
- 1.8.5. To discover whether support systems are helpful and beneficial to HIV-positive women.

## **1.9. THE RATIONALE FOR THIS STUDY**

Vasquez (2004) claims that in South Africa, nearly 15% of the population of 45 million is HIV-positive and the South African 2004 National HIV and Syphilis Antenatal Sero-Prevalence Survey shows that the HIV cases in the Western Cape have almost doubled since 2001 and prevalence now stands at 15.4%. HIV is thus not only a serious threat in our country, but also in our Province (Caelters, 2005:). Not only is HIV/AIDS a serious physical health risk, it also “has the potential to damage global mental health most seriously” (Freeman, 2004:140).

As there is at present no cure for HIV/AIDS, many young women are being confronted with a diagnosis of a terminal illness and studies show that there are various ways in which one may react to a terminal diagnosis. Elizabeth Kubler-Ross (1970) has identified five coping stages. Stress, depression and learned helplessness are also all possible ways in which people may react when confronted with an HIV-positive diagnosis which is not only at present a terminal illness, but is also a highly stigmatized disease often sensationalised in the media.

However, although there is as yet no cure for HIV/AIDS, the incubation phase means that the individual continues to live an asymptomatic life for many years and death may not be imminent unless the person is only diagnosed once he/she has reached the final stage of the disease. Furthermore, even if one is at Stage 4 of HIV/AIDS, ARV treatment decreases the viral load and increases the CD4 count.

A reader of the *Sunday Times* (Mapongwana, 2006:22) tells how she started taking ARV's in 2003 when she weighed only 29 kgs. and her CD4 count was down to 0.4. Today she is still alive and is an HIV/AIDS counsellor and educator.

In South Africa the incubation period is less than that of industrialized nations but, as stated previously in this chapter, it is said that if people can eat nutritious food, try to minimize stress and keep free of other diseases which also weaken the immune system, the incubation period could be prolonged. Even if they do become ill, they can still expect to live a reasonable life for a longer period of time with the use of antiretroviral therapies (Whiteside & Sunter, 2000; Kauffman, 2004).

Whiteside and Sunter (2000:9) proclaim that ..“it is hoped that AIDS can be turned into a manageable chronic disease like diabetes. In this event, people could expect to live a normal life span though they would remain infectious”. It is therefore important to learn how women react and cope when they are diagnosed HIV-positive and how they may be helped to manage their lives more effectively, healthily, positively and meaningfully.

#### **1.10. THE SIGNIFICANCE OF THIS STUDY**

The significance of this study is that it can make a contribution to a better understanding of women's reactions to an HIV-positive diagnosis. It can also contribute to establishing how the support systems which they utilise help them to cope and manage their lives more effectively.

#### **1.11. THE STRUCTURE OF THIS REPORT**

This chapter commenced by outlining the problem statement and clarifying the important concepts of HIV and AIDS used in the study. The background to the research problem was provided which included discussions of the HIV/AIDS Pandemic, HIV/AIDS in Africa and South Africa, women and HIV/AIDS, the social and cultural meanings of HIV/AIDS, the progression of HIV/AIDS and the means to combat this progression. The topic, context and main research questions and objectives were detailed and the rationale and significance of this study were discussed.

Chapter 2 consists of the literature review relating to the social perceptions regarding HIV/AIDS and discusses the “scientific”, media and government mixed messages regarding this disease that are communicated to the public. Attention is also focussed on the issues of stigma and women, as relating to the social perceptions regarding HIV/AIDS. Chapter 3 continues the literature review by describing the various ways in which individuals may react to a diagnosis of a terminal illness and how support systems may be used to alleviate this distress. Chapter 4 presents the methodology and data collection procedures used in this study. Chapter 5 discusses the findings related to the stated objectives and in Chapter 6 conclusions are reached and recommendations, based on these conclusions, are suggested.

University of Cape Town

## **CHAPTER 2 LITERATURE REVIEW:**

### **SOCIAL PERCEPTIONS REGARDING HIV/AIDS**

#### **2.1. INTRODUCTION TO THE CHAPTER**

This chapter presents a literature review of the issue of social perceptions regarding HIV/AIDS. The role played by formal and informal institutions as well as the role of language in the formation of social perceptions is discussed. Sources of mixed messages are outlined. “Scientific” messages include those concerning risk groups and behaviours and dissident views and alternative theories. Media messages are communicated by means of sensationalist reporting, scare tactics and using the metaphor “AIDS as Death”. Government messages concerning HIV/AIDS lead to the politicization of HIV/AIDS. Important issues in this regard are those of traditional versus western treatment, questioning the link between HIV and AIDS and the negative effects of government intervention. Finally, also concerning social perceptions, the issues of stigma regarding HIV/AIDS and the position of HIV-positive women are discussed.

#### **2.2. SOCIAL AND CULTURAL MEANINGS**

“AIDS is no ‘ordinary’ epidemic. More than a devastating disease, it is freighted with social and cultural meaning” (Nelkin, Willis & Parris, 1991:1). Thus the experience of living with HIV/AIDS cannot be separated from the social construction and, therefore, the social and cultural meanings related to HIV/AIDS. These meanings are developed by various social institutions.

The following section considers the ways in which formal and informal institutions including language influence perceptions and meanings. Kaufman (2004:18) defines institutions as ... “the humanly devised constraints that we place (or are placed by others) on our lives” to highlight the point that although they are meant to provide clarity regarding these interactions, they may also do harm.

### **2.2.1. Formal Institutions**

Formal institutions, which include national constitutions and laws, have an important impact on society. As will be discussed in greater detail later in this chapter, the ambivalence of government leaders in South Africa regarding HIV as the cause of AIDS has been criticised and may have led to widespread confusion amongst the general population. For example, AIDS was said, by AIDS dissidents, to be “the result of poverty and lifestyle choices – and even the result of antiretroviral medication” (Nattrass, 2004:49).

This view was widely held. If, however, it was true what the dissidents claimed and that HIV was not infectious and did not cause AIDS, then “the safe sex message of responsible sexual decision-making, issues of gender and of domestic violence and the recognition of the seriousness of the epidemic, fall away” (Crewe, 2000:25/6). The resulting mixed messages and confusion led the Democratic Alliance’s Robin Carlisle (Essop, 2005:6) to say that “We cannot have a situation where more than 35% of people don’t know how they are infected”.

### **2.2.2. Informal Institutions**

Informal institutions are “the codes of behaviour that individuals live their lives by” and they sometimes have a stronger influence than formal institutions and dictate much of our interactions with others (Kauffman, 2004:19). How men and women interact and function in society is primarily determined by local custom. In this regard, informal institutions dictate codes of behaviour in the form of norms, customs, traditions and personal ethics by which people live their lives. Social norms and customs that directly or indirectly affect HIV transmission are the role and the treatment of women in South African society (Kauffman, 2004). This will be expanded upon later in this chapter.

The way in which these customs and norms are imparted is by means of language.

### 2.2.3. The role of language in social perceptions

Our experience of being in the world is largely socially constructed and the ways in which one learns about and understands a disease and the moral judgments made about the causes of illness, are all mediated by language, which is seen as actually constructing that reality (Parker, 1992; Lupton, 1994; Soskolne, Stein & Gibson, 2003). Language is central to the meaning of illness and, regarding HIV/AIDS, Lupton (1994:1) claims that “few other diseases in this century have been greeted with quite the same degree of fear, loathing and prejudice against those who develop it.”

Furthermore, language decrees who is considered to be ‘at risk’ of spreading or developing a disease and how they should be treated. HIV/AIDS is at present pre-eminently a disease of sub-Saharan Africa and in South Africa, blacks are disproportionately affected. The HIV statistics of South Africa are based predominantly on the annual antenatal HIV surveys which are conducted in national public health facilities. According to the Department of Health (as cited in van der Vliet, 2004:82) “Eighty per cent of pregnant women use these facilities and 85 per cent of the women tested in 2000 were black.” This means that “all the baggage of ‘race’ and ‘culture’ have been packed in with the issue” of HIV/AIDS (van der Vliet, op cit).

Furthermore, HIV/AIDS has been presented as a “killer disease” for which there is no cure and, for many people, an HIV-positive diagnosis means death and a body ravaged by opportunistic infections, as vividly depicted in videos such as *‘Angels in America’* and in the movie *‘Philadelphia’*. Any hope is thus considered unrealistic, and helplessness and hopelessness may prevail as some people may conclude that there is nothing that anyone can do to change this situation.

As a result of social perceptions HIV-infected persons may fear being stigmatised. This fear could lead to denial and non-disclosure of their status, making it more difficult for them to seek support, information and treatment. The social meaning, driven by the language of HIV/AIDS thus affects the consequences of AIDS, not only for AIDS sufferers and their families but also for the public (Smith, 1991).

The language of HIV/AIDS has been significantly shaped by scientific, media and government messages since 1981 when the public first became aware of this new disease.

### **2.3. “SCIENTIFIC” MESSAGES**

Mixed messages from the scientific community and those who hoped to portray their views or theories in scientific terms regarding HIV/AIDS started with the announcement of a new disease.

#### **2.3.1. The advent of AIDS**

AIDS first came to the public’s attention on the 5<sup>th</sup> June, 1981, when a “gay-related immune deficiency,” as identified in the Centre for Disease Control (CDC) was reported in the pages of the *Morbidity and Mortality Weekly Report* (MMWR), a widely circulated report on infectious diseases and deaths produced by the CDC’s in America (Whiteside & Sunter, 2000:1; Cochrane, 2004:24). The CDC’s initial alarming report heralded the discovery of an immunodeficiency syndrome in gay men and told of 5 young men, all active homosexuals, who had received hospital treatment in Los Angeles in the United States of America, from October 1980 to May 1981, for *Pneumocystis carinii* pneumonia and Kaposi’s sarcoma. It was further stated that two of these patients had died.

The editor of the MMWR concluded that: “The fact that these patients were all homosexuals suggests an association between some aspect of a homosexual lifestyle or disease acquired through sexual contact and (the) pneumonia” (Lupton, 1994:8; Cochrane, 2004:24/25). Thus, from the outset a risk group had been identified.

#### **2.3.2. Risk Groups and Behaviour**

AIDS has been presented as a condition affecting social and/or demographic minorities whose ‘exceptional’ behaviour has put them at risk and who are now reaping the rewards of their ‘depravity.’ It can thus be seen that the meanings attributed to diseases .. “may be used to impute blame, to allow moral judgments to be expressed, to obscure patriarchy and paternalism, to maintain powerful interests, and to exert control” (Lupton, 1994:5).

Diseases affect people in various ways and these are influenced by the meanings which we attach to these illnesses, and our responses are guided by our interpretation of these meanings. Furthermore, disease has often been connected with moral issues. In literature, the words 'sickness' and 'sin' have long been linked. Fear, loathing, prejudice and discrimination against people with HIV/AIDS is widespread. Weeks (1987:8) writes: "The truth is that while AIDS as a syndrome of diseases has common features in all parts of the world, the social meanings it gives rise to can be profoundly different" (Weeks, 1987:8).

This means then that although AIDS is like many other illnesses which devastate lives, what is remarkable about AIDS .. "is not simply its virulence, but the weight of symbolic meaning that it carries" (Weeks, 1987:17). Individual failings, especially regarding sex, social marginality and moral inadequacy are all associated with AIDS victims. Weeks (1987:2) states that "AIDS has become the symbolic bearer of a host of meanings about our contemporary culture: about its social composition, its racial boundaries, its attitudes to social marginality; and above all, its moral configurations and its sexual mores."

#### 2.3.2.1. Marginal populations

AIDS as a new disease in the early 1980s at first seemed related only to the gay minority community. A favourite news headline was "The gay plague" and people with the disease were blamed for it. However, further risk populations soon emerged in the United States of America and the risk categories of the four H's, viz. homosexuals, heroin users, haemophiliacs and Haitians, became widely publicized. (Cochrane, 2004). AIDS was seen to be confined to marginal, and with the exception of haemophiliacs, politically and morally embarrassing communities (Weeks, 1987; Cochrane, 2004).

With 'risk groups' rather than 'risk behaviours' being identified, the wish to see AIDS as a problem of the other, the non-respectable and the out-of-control, was intensified (Frankenberg, 1987). This association of AIDS with marginal populations such as gay men and black people meant that ... "anxiety about AIDS was thereby able to draw on pre-existing tensions concerning race and sexual diversity.." (Weeks, 1987:9).

“AIDS presents, in short, a constellation of issues encompassing racism, poverty, homophobia, sexism, commodified health care (and its availability), censorship, sex, drugs and death” (Smith, 1991:3).

#### 2.3.2.2. Retribution

AIDS was seen as God’s or nature’s judgment on moral decay and some argued that “Those who commit the sin of fornication .. must bear the cost” (Nelkin, Willis & Parris, 1991:23). ‘Rituals of decontamination’ abounded and there were calls for “enforced quarantine, mandatory screening, closing of gay bars, constraints on marriage and childbearing, and exclusion of infected persons from work, restaurants and schools” (Nelkin, Willis & Parris, 1991:4). In the 1980s, the entire population of Cuba was tested and HIV-positive individuals (mostly soldiers returning from the Angolan war) were isolated in ‘sanitoria’ (Whiteside & Sunter, 2000; Irwin, Millen & Fallows, 2003; Natrass, 2004).

#### 2.3.2.3. Risk activities

The mid 1980s saw the rapid escalation of media and popular hysteria regarding AIDS and issues such as promiscuity, permissive lifestyles and drug taking. In the United States of America, the gay communities themselves became very active by providing social aid and health care to people with AIDS, whether gay or not and instead of risk categories, they emphasized risk activities which could be reduced by using condoms, cutting out unprotected sex activities and by injecting drug users not sharing needles. Education as prevention was seen as essential (Weeks, 1987).

It also became clear during the mid 1980s that AIDS was a health threat of global proportions and which, in world terms, largely affected heterosexuals. Heterosexual transmission meant that women were thus also categorised as being either safe, meaning middle class and married, or dangerous and promiscuous. Prostitutes were represented as a locus of contagion and were seen as ‘dangerous reservoirs’ of infection (Lupton, 1994:17).

“The drive to assign guilt or blame in relation to AIDS has been a persistent feature of the epidemic” (Irwin, Millen & Fallows, 2003:19). Blame is also imputed when questioning the origin of HIV/AIDS.

### **2.3.3. Dissident views and alternative theories regarding HIV/AIDS**

By 1983 the virus causing AIDS had been identified although it still remains unclear where the virus came from (Evian, 2000). Despite the origin of HIV/AIDS being unknown, various causes have been mooted and the debate around this issue is also seen as an attack on certain groups.

#### **2.3.3.1. Alleged origins of HIV/AIDS**

A range of theories regarding the origins of HIV/AIDS have been mooted – from witchcraft to science. Some believe the Western media has created it to stigmatise Africans, others that the churches are trying to frighten people against loose sex. Further dissident theories are that the virus may have been brought from the Moon by Americans. Alternatively, some argue that it may have been manufactured by American scientists through genetic engineering ostensibly for use in biological warfare for genocide against black populations (Agadzi, 1989; Duh, 1991; Mbuya, 2000; Usdin, 2003).

Sam Nujoma, President of Namibia, is recorded as saying : “It is also an historical fact that HIV/AIDS is a man-made disease, it is not natural”, and Colonel Muammar Qadhafi, President of Libya, wondered if the laboratories of the CIA had created the AIDS virus (cited in Usdin, 2003:16). In South Africa, *Drum* published an article titled ‘Is AIDS a conspiracy against Blacks’, giving credence to tales that in their last days of office, the rulers of the apartheid government had deliberately introduced it to check the advance of African liberation (cited in Phillips, 2003). Dr. Wouter Basson, known as ‘Dr Death’ has been accused of sending HIV-positive spies to “deliberately infect the black population” (Usdin, 2003). The role of genetics has also been mooted as a factor as it is said that the GcIF gene occurs more frequently in black persons and may explain a high AIDS rate in black people (Duh, 1991).

#### 2.3.3.2. The African jungle issue

It has often been reported that AIDS originates from Africa with the chimpanzee or macaque monkey as the carrier. This connection of Africa to the origin of HIV/AIDS once again raises the issue of racism attached to this disease (Agadzi, 1989; Chirimuuta, 1989; Duh, 1991). Narratives of African AIDS construct the origin of this disease as a product of nature as much as culture – “conjured out of the primordial (jungle) or caught from animals imagined side by side with Africans” (Cochrane, 2004:3), intimating that AIDS is represented as emblematic of African’s underdevelopment, as if a lack of Western-style culture, rather than a virus was the cause of AIDS in Africa. “The problem however with dwelling on the epidemic’s roots is that people distort the speculations to apportion blame and to create scapegoats, feeding into racism and xenophobia” (Usdin, 2003).

#### 2.3.3.3. The single virus theory dissidents

The single virus theory has also not been accepted by all scientists and members of the public. In 1992, participants at the Alternative AIDS Conference in Amsterdam mounted an assault on the theory that HIV causes AIDS, leading to increased attention to dissidents’ views in the popular and scientific media (Cochrane, 2004).

#### 2.3.3.4. Dissident views regarding treatment

These dissident views extend to the realm of treatment regimes regarding HIV/AIDS. Dissidents proclaim that healthy living and eating will obviate the need for medication which is seen as toxic, and in some instances lethal.

All these views have been picked up by the media and publicized widely, thus presenting world wide coverage of these mixed messages regarding HIV/AIDS.

## 2.4. MEDIA MESSAGES

From the time that the symptoms of AIDS were first recorded in the early 1980's, the news media has had a key role to play in constructing public understandings of HIV and AIDS in countries all over the world. Stein (2001) avers that the media's role in portraying and reporting on HIV/AIDS cannot be overestimated, as ... "Media audiences are especially dependent on the media as information sources and for guidelines about how to feel and how to react" (Stein, 2001:4). Media reporting has shown AIDS to be not only a medical condition, but one which is redolent with cultural meaning.

In this regard, "The ways in which the phenomenon of AIDS has been represented in the entertainment and news mass media have played an important role in the development of shared cultural meanings about AIDS" (Lupton, 1994:9). Many large-scale studies of AIDS-related knowledge, attitudes, beliefs and behaviour, show the importance of the mass media as major sources of information about AIDS, whether this be accurate or distorted (Lupton, 1994).

"HIV/AIDS brings together a potent mix of sex and death, science and politics and deep-seated divisions and inequalities between North and South, rich and poor, and men and women" (Stein, 2001:4). HIV/AIDS, therefore, has great journalistic potential and by informing and educating, the media could be .. "a powerful tool that can be mobilized against HIV/AIDS" (Stein, 2001:4). Notwithstanding, Mombe (2004:31) avers that "Many people in Africa are dying of HIV/AIDS for lack of basic knowledge about how to manage AIDS."

Stein (2001) reports that 92% of the South African population have access to radio, 76% to television and 55% to newspapers. Thus the media could be used to promote health and development ... "especially since high-risk populations often have little access to formal education" (Stein, 2001:5). However, news media are profit-making concerns and news items must sell and sell well to ensure financial sustainability. Therefore, HIV/AIDS articles usually rely on the news value associated with the disease rather than being instruments contributing to social change (Stein, 2003).

### **2.4.1. Sensationalist reporting**

The HIV/AIDS issue has spawned huge media interest and coverage and linking AIDS to homosexuality, heterosexual promiscuity, prostitution and injecting drug use, have all assisted in making AIDS a media sensation. Usdin (2003, 2003:61) states that “The media has fed the frenzy of discrimination against minorities and groups perceived somehow to be ‘deviant’” (Usdin, 2003:61).

In this study it was found that the majority of women interviewed had suffered from stigma as a result of social perceptions regarding HIV/AIDS. It is suggested that these social perceptions are fuelled by sensationalist and biased media reports concerning risk groups and behaviours pertaining to HIV-positive individuals.

HIV/AIDS is an incurable medical condition and to inform the public of the risks of this disease in the 1980s scare tactics were commonly used by the media .

### **2.4.2. Scare tactics**

“Regrettably, scare tactics were the order of the day in the initial campaigns designed to alert the public to the dangers of AIDS” and this exacerbated discrimination and stigma (Usdin, 2003). Various media campaigns have been run to mobilize a fear or shock reaction to HIV/AIDS. In 1986 the British media ‘Don’t die of Ignorance’ campaign used images of massive tombstones carved with the word ‘AIDS’ and images of volcanoes and icebergs to show that AIDS was a hidden threat to everyone. In Australia in 1987 the ‘Grim Reaper’ period of AIDS reporting marked an intensification and dramatization of AIDS coverage by their news media with the clear message of ‘AIDS KILLS’ (Usdin, 2003:23). The grim reaper was portrayed as a ‘horrifyingly skeletal and skull-headed figure swathed in a black hood carrying a scythe and (incongruously) a bowling ball’ which would be aimed by the figure of Death to knock down and kill ‘ordinary’ people. “The grotesque and medieval figure of the ‘Grim Reaper’ thus became the definitive sign of AIDS, bringing with it its older meanings of death, famine and plague, and divine retribution” (Lupton, 1994:52).

A study by Ross (as cited in Lupton, 1994:37) on the American press during the early 1980s found metaphors commonly used to explain AIDS: 'AIDS as a plague', 'AIDS is death', allowing little hope for those who have AIDS, 'AIDS as punishment for sin' and 'AIDS as the other', which serves to stigmatize people living with AIDS.

#### **2.4.3. AIDS as 'Death'**

Even though Mbuya (2000:18) states that "A finding of HIV is certainly not an immediate death sentence", doomsday predictions of AIDS are common – that everybody who contracts the virus will die and no effective treatment or vaccine will be discovered. "Advocates of this view see AIDS as a threat to the very existence of the human race" (Dossier, 1989:47). The disease has been described as fatal and any resistance to it, hopeless (Weeks, 1987).

The media publicised AIDS as an apocalyptic disaster which threatened to decimate the population (Lupton, 1994) and this was reiterated by *Time Magazine* in 2001 when it called AIDS 'humanity's deadliest cataclysm' (Phillips, 2003). HIV/AIDS infected people are constantly reminded that they are most probably going to die. "You turn on the television or open a newspaper and, in the context of an item of AIDS, you will see yourself described in terms which make it clear that, in society's eyes, you are finished" (Grimshaw, 1987:256). Nearly two decades later, the news remains the same. Local newspaper headlines read: "Huge rise in Aids deaths in SA, says TAC" (Caelers, 2005:5) and "HIV sends death rate soaring for young women, says report" (Witbooi & du Plessis, 2006:1).

Stein (2001:9) writes that "First world coverage of AIDS in sub-Saharan Africa has an unfortunate tendency to fall into the category of what can sometimes be called 'Death Voyeurism' and the themes of disaster, devastation and hopelessness predominate when referring to AIDS in sub-Sahara.

#### 2.4.4. Reporting in South Africa

In 1982, when HIV was first identified in South Africa, it was male homosexuals who bore the brunt of the blame. However, by the late 1980s, as HIV became more prominent among heterosexuals, especially blacks, they, too, became the victims of white racist accusations. As elsewhere in the world, risk groups and behaviours were identified and South African AIDS news clippings before 1995 referred to “gay plagues and black deaths, innocent victims or guilty sinners and malicious infectors” (Stein, 2001:9).

Phillips (2003:33) states that it is not surprising that blame was imputed along racial lines as ‘blaming the victim’ had a ‘long pedigree in South Africa’s epidemic history.’ In 1990 a pamphlet was distributed, calling for “whites to be insulated against Africans so they could ‘survive in an AIDS sea’” (van der Vliet, 2001:157). In 1990 it was decided by the director of the Highveld Blood Transfusion Service not to take blood from Africans and Coloureds, as they would likely be HIV-positive (Phillips, 2004).

In South Africa “the first awareness campaigns focused on funerals and hopelessness (Usdin, 2003:23) and there has been a proliferation of sensationalist and alarmist reporting and a depiction of AIDS ‘victims’ as ‘sufferers’ dying of AIDS, as passive, submissive, hospitalized and useless (Stein, 2001). Journalist Mark Gevisser (cited in Stein, 2001:7) says that “..the media often kills people with AIDS long before they are ready to die, fuelling the public misconception that if you have it, you might as well be dead..”

According to a front page Cape Town newspaper report (Cape Argus, 2005:1) there was a 57% increase in deaths between 1997 and 2002 in South Africa, the biggest increase occurring in women and people aged between 20 and 49. Stats S.A. head Pali Lehohla said that the study “provides indirect evidence that the HIV epidemic in South Africa is raising the mortality levels of prime aged adults”. South African Institute of Race Relations (SAIRR) researcher Marco MacFarlane stated that “by 2011, more people would die of AIDS in South Africa than all other causes of death combined” (Cape Argus, 2005:1).

#### **2.4.5. The effect of the mass media presentation**

The media has thus spoken and the general world agrees that the HIV/AIDS infected person has a definite identity, that is one of being a member of the 'other', usually a marginalised group, behaving in ways unbecoming to societal norms, certainly getting one's 'just desserts' and worthy of derogatory and scornful treatment. Furthermore, this person is doomed to a most unpleasant illness and death and he/she only has him/herself to blame for this state of affairs.

This is a very simplistic, generalised and biased outlook, but unfortunately this scenario, as generated by the media, has become the real world for many people who find themselves in the situation of being diagnosed HIV-positive. "Far more than any other disease, illness or condition reported in the news media, discourses on AIDS have invoked stigmatization, discrimination, homophobia, racism, prurience, objectification, panic, a sense of emergency, moral meanings, and imagery associated with plague, sin, divine retribution, leprosy, and holocausts" (Lupton, 1994:120).

As well as scientific and media messages, government messages also contribute to social perceptions of HIV/AIDS.

#### **2.5. GOVERNMENT MESSAGES**

The mixed messages around HIV/AIDS as communicated by the scientific world and the media also continues to be conveyed by our South Africa government.

##### **2.5.1. The Politicization of HIV/AIDS**

In post-apartheid South Africa, HIV/AIDS news coverage has often concerned conflict around AIDS policy and "has achieved the status of 'high politics'" (Stein, 2001:9). The 1995/96 *Sarafina II* musical production which was meant to provide AIDS education to the masses, cost R14.2 million using unauthorized government expenditure and a flawed tendering process. Furthermore, the message it sent was seen as being 'far from clear' and heavy criticism of the government was evoked (Nattrass, 2004; van der Vliet, 2004).

This established a cycle of “responses and counter-responses in which actors have competed to set the agenda for AIDS in South Africa” (Schneider, 2001).

Following closely on the heels of Sarafina II in 1997 was the issue of Virodene PO58 for which the entire cabinet of the government “sought endorsement for its use as a treatment for AIDS” (van der Vliet, 2004:56). However, as established ethical and procedural protocols for drug research had not been followed, the Medicines Control Council branded it as dangerous and refused to approve the drug. Unfortunately, the hopes of people living with HIV/AIDS had been falsely raised. A new African miracle cure had not been discovered.

When the presiding Health Minister Dlamini-Zuma announced in 1998 that antiretroviral therapy would not be made available for mother-to-child transmission prevention (MTCTP) because of the cost and the fact that the drugs were toxic or created drug resistance, the Treatment Action Campaign (TAC) was formed. Their aim was to make treatment more accessible and affordable by putting pressure on both the government and pharmaceutical concerns (van der Vliet, 2004). The TAC led many attacks on government policy and they finally took the government to court on the issue of MTCTP, and won, forcing state provision of Nevirapine to HIV-positive pregnant mothers which significantly reduces mother-to-child transmission of HIV.

The mixed messages around HIV/AIDS treatment created a traditional versus western stance regarding medication.

### **2.5.2. Traditional versus Western treatment**

South Africa Health Minister, Dr. Manto Tshabalala-Msimang, has said that people should make up their own minds as to whether they prefer alternative medicines or antiretroviral treatment (Caelers, 2005). When these views are endorsed by political leaders, such dissidence leads to implications for the management of HIV/AIDS at national as well as local levels.

The controversy around medication versus nutrition regarding HIV/AIDS treatment rages on. At the recent 16<sup>th</sup> International AIDS Conference in Toronto, South Africa's current Health Minister, Dr. Manto Tshabalala-Msimang again, as she had done at the past three international AIDS conferences, "emphasised nutrition as an 'alternative' to antiretroviral medication" (Thom, 2006:10).

The TAC's Mark Heywood said at the conference that: "There has been an absence of moral, political and strategic leadership from the ANC and the government" and he accused Dr. Tshabalala-Msimang of "repeatedly promoting and juxtaposing the value of traditional medicine as opposed to Western medicine", thus "creating a pseudo-politics around 'Western versus African' traditions of healthcare" (Thom, 2006:10).

### **2.5.3. Questioning the link between HIV and AIDS**

In South Africa, President Thabo Mbeki has questioned the link between HIV and AIDS and the extent of AIDS mortality and has implied that poverty is the cause of AIDS. In 2000 he created the 'Presidential International Panel of Scientists of HIV in Africa', comprising conventional scientists and dissidents (who believed that poverty caused AIDS) to explore "all aspects of the challenge of developing prevention and treatment strategies that are appropriate to the African reality" (Usdin, 2003; Natrass, 2004:50). President Thabo Mbeki's questioning of the cause of AIDS became highly politicized and critics of Mbeki's association with AIDS 'dissidents' were accused by government officials as being anti-government and even racist (Stein, 2002).

### **2.5.4. Negative effects of government intervention**

Natrass (2004) and Kauffman (2004) claim that the President's interventions in the AIDS debate and the inaction of the government most probably resulted in widespread confusion among the general population. This inaction has also delayed the provision of antiretroviral drugs which, although now available, has still not reached the majority of those needing treatment. The British Medical Journal, *The Lancet* has accused South Africa of "continuing to drag its feet over anti-retroviral roll-out, which the publication describes as 'pitifully poor' " (Caelers, 2006:4).

Furthermore, the issues of toxicity, drug resistance and drugs versus healthy eating as treatment, are still being debated which could cause further confusion in the minds of the general population who, because of these arguments, may be dissuaded from seeking medical treatment.

The mixed messages from science, the media and government play an influential role in shaping social perceptions regarding HIV/AIDS. More importantly, these social perceptions may lead to the stigmatization of HIV-positive individuals.

## **2.6. STIGMA AND HIV/AIDS**

“Shame and stigma reinforce the silence around HIV/AIDS and present one of the major obstacles to global efforts to defeat the epidemic” (Usdin, 2003:57). AIDS stigma may be shown through discrimination, rejection, avoidance of people infected with HIV/AIDS, ostracism and violence (Usdin, 2003). As previously discussed in this chapter informal institutions dictate who is shunned by society and stigmatized, and discrimination, violence and rejection may be suffered by people who disclose their positive HIV status. The extreme penalty can also be inflicted and in South Africa, in December 1998, Gugu Dlamini was murdered by the people in her community after she publicly revealed that she was HIV-positive (Usdin, 2003:56).

Sontag (1991:101) avers that AIDS is a highly stigmatised disease and “its capacity to create spoiled identity,” is far greater than any other disease. People with sexually transmitted diseases have always been stigmatized, because they are associated with behaviours which are considered deviant or immoral. HIV/AIDS divides people into ‘them’ and ‘us’ (Usdin, 2003) and Gilmore and Somerville (1994) identify metaphors which are used in describing HIV/AIDS, which include “HIV/AIDS as death; as punishment; as crime; as war; as otherness; as horror; and the HIV sufferer as a villain.” Revealing one’s HIV-positivity is seen as bringing ‘shame’ on families. (Usdin, 2003) ”.

### **2.6.1. Studies concerning stigma**

Poku (2005:171) describes a South African survey, based on focus group discussions with HIV-positive individuals, which reports that negativity towards HIV-infected people, even when shown by only a minority of community members, and the fear of negative reactions is strong enough reason for people living with HIV/AIDS (PLWHA) not to disclose their positive status.

A study of women at a health clinic in Dar es Salaam, Tanzania showed that “fear of violence and abandonment was cited as the main reason for not saying they were infected” and in Kenya “more than half of a group of HIV-positive women hid the news from their partners for similar reasons” (Usdin, 2003:54).

Kahn (2004:1) conducted research which explored the personal experiences of five HIV positive people, four of whom were women, in an urban, informal settlement in Cape Town. In-depth interviews and a focus group was used to provide an understanding of “how individual and social processes intersect and shape experiences of HIV positive individuals”. When asked if HIV positive people should disclose their status to their sexual partners, all the women, in contrast with the male respondent, advocated non-disclosure. They had all had negative experiences when disclosing to their sexual partners, who denied the possibility of their own HIV positive status. In this study, women saw disclosure as a threat to an intimate relationship and the cost of disclosure to be possible rejection.

### **2.6.2. The effects of stigma**

Stigma and discrimination against HIV-positive individuals are described as “.. the greatest barriers to preventing further infections, providing adequate care, support and treatment and alleviating impact” (Parker and Aggleton, 2002:5), as HIV-positive individuals have to weigh up the costs of disclosing their status. They may therefore prefer to ‘pass as normal’ rather than HIV-positive (Rohleder and Gibson, 2005:3). This non-disclosure deprives women of the support they need to stay healthy. (Usdin, 2003).

Any potentially life-threatening information is devastating and AIDS sufferers not only live with the uncertainty of the progression of their disorder, but because of the stigma attached to their diagnosis, they “must live with the inner conflict of who to tell or not to tell, and of how to manage their sexual and work lives” (Smith, 1991:2). Being HIV-positive may mean that people are rejected and ostracised, which can lead to marital, relationship and family break-up, loss of job and housing and loss of friends.

Many people feel that they cannot inform relatives and friends of their HIV-diagnosis for fear of being labeled ‘bad’ or ‘sinful’ and being stigmatised and rejected. Therefore they do not have access to the traditional support systems, namely those of the extended family and maybe traditional healers. Even if they do confide and are accepted, they may still not receive the type of support needed, perhaps due to a lack of understanding of the problem. Thus, at a time when social support is most needed, it may become least available (Smith, 1991; Mbuya, 2000). The fear of ...’very visible social punishment’ and stigmatization could also prevent people from being tested and if they are HIV-positive, they may continue to spread the virus to others (Kauffman, 2004:23).

Thus, “the stigma associated with HIV/AIDS feeds inequalities of gender, sexuality, class and race” (Usdin, 2003:62). Usdin (2003:65) writes that “..stigma reduces people’s autonomy and ability to make protective choices, thereby increasing their personal risk as well as influencing the epidemiology of the epidemic”.

As with stigma, social and cultural perceptions and institutions play an important role regarding women and HIV/AIDS.

## **2.7. WOMEN AND HIV/AIDS**

Women are biologically more vulnerable to HIV infection and their unequal social standing in society renders them less able to protect themselves against being infected. HIV/AIDS prevention programmes focus on the issue of personal responsibility, but for many women who are raped or “who have no power to negotiate safer sex within their relationships” personal control is not possible (Usdin, 2003:60).

AIDS affects women, not only as people who are HIV-positive, but also in their multiple societal and family roles such as wives, mothers, partners, income providers and educators (Mwale & Burnard, 1992). Various factors contribute to a woman's risk of contracting HIV/AIDS and factors that seem to influence levels of HIV/AIDS prevalence are those related to poverty, inequity, gender imbalances, circumcision practices and the level of STD's (Fransen, 1998). Women may have lower educational training and limited access to information. They may be expected to produce many children who could provide economic benefit in old age, or, even if they wish to, they may have no say in insisting on condom use by partners. In rural areas, women often stay behind while their husbands seek work in the cities and only visit home once a year. Women often have no means of income and may be dependent on partners for economic support, and also be subservient to them if cultural norms so dictate. All of these factors influence behaviour and HIV infection levels in the population (Fransen, 1998).

Soskolne (2003:9) writes that "Black women, living in township areas, are one of the most marginalised groups in South Africa, and are most vulnerable to poverty and violence." Poverty and unemployment increase dependent relationships increasing the vulnerability of women to 'coercive and risky sex' (Usdin, 2003:37). Usdin (2003:45) writes that .. "black, poor, women faced a triple oppression (of race, class and gender). Now, AIDS makes their load even heavier". Black women in South Africa, who are also most affected by HIV/AIDS "generally occupy the lowest rungs on the hierarchy of social, economic and political power" (Rohleder & Gibson, 2005:3). These HIV-positive women are therefore most likely to suffer stigma and discrimination (Shisana & Simbayi, 2002).

### **2.7.1. Effects of the social construction of HIV/AIDS on women**

"For women, the social construction of HIV/AIDS cannot be torn apart from the oppression and regulation of women under patriarchy, and from gendered constructions of masculinity and femininity" (Soskolne, 2003:1). Black women, especially those living in Africa, have been seen as 'carriers' of the disease and therefore viewed as being dangerous (Soskolne, 2003).

LeClerc-Madlala (2001:38) conducted an ethnographic study in a community in the Durban area and states that “The Zulu interpretation of AIDS is shown to be intimately bound up with the overall socio-cultural construction of femininity, in which women are seen as both the sources and disseminators of the disease.” This study is seen to support other research in Africa which shows that women are blamed for the cause and spread of HIV/AIDS (LeClerc-Madlala, 2001:39). This can incur violence or rejection as they are then accused of ‘bringing AIDS’ home and not only does violence contribute to the spread of HIV, but it also increases levels of violence against women (Usdin, 2003:54).

Strebel (1995) maintains that constructions of the out-of-control sexuality of black women still persist and is perceptually linked to the spread of AIDS in Africa. Anomalies also exist in that black women are either portrayed as dangerous, in that as the ‘other’, she carries risks not only for whites, but also for black men (Joffe, 1999). Conversely, she is portrayed as a victim of violence, abuse, poverty and AIDS and these discourses, “while acknowledging the precarious position of black women in society, also work to destroy their agency and silence their voices”, as victims are seen to accept their oppression (Soskolne, 2003:3).

### **2.7.2. Effects of socio-cultural-economic issues on women**

Although HIV is more common among those who display high risk behaviour and have many sexual partners, in the developing world most cases result from ordinary sexual relations within regular partnerships (Mwale & Burnard, 1992). In South Africa, the rate of infection transmitted through heterosexual intercourse is most probably 80% (Loewenson & Whiteside, 1998). Therefore, cultural institutions and issues play an important role in the spread of HIV/AIDS. Even if a wife is infected with an STD by her husband, it may be culturally unacceptable for her to say anything about this and she may also not be able to insist on his using condoms. Furthermore, they may want children and condom use would prevent this (Mbuya, 2000). Unfortunately, where women are seen as having lower status than men, both within sexual relationships and within the wider society, there is a restriction on women’s ability to protect themselves from becoming infected, as they often have little autonomy and power regarding sexual matters.

Mwale & Burnard (1992:13) state that “For many women in developing countries, the threat of AIDS begins with a lack of control over the sexual lives of their husbands outside marriage”. In reality, many women are dependent on their male partners for financial support and they may thus be forced to engage in unprotected sexual intercourse or risk having their financial and social support cut off. Unfortunately, the social and economic status of many women make it impossible for them to challenge their partner’s behaviour. “Many women who are at risk for HIV infection, face formidable obstacles to changing their sexual behaviour. These include lack of knowledge, denial of risk status (by the women or her partner), embarrassment about discussing sex and AIDS, difficulty in asserting herself, lack of control in relationships with men and lack of partner cooperation” (Mwale & Burnard, 1992:38).

For those who live in a socio-economically deprived environment, there is often a day-to-day struggle for survival and women often rely heavily on the generosity of their partners to provide for their needs. Shabodien (2003) says that Khayelitsha is the township with the highest prevalence of both poverty and HIV in the Western Cape and “HIV/AIDS is a very tangible threat in their community where poverty is endemic and sickness an unsustainable financial and emotional burden” (Soskolne, Stein & Gibson, 2003:5). The health MEC, Pierre Uys, reports that in areas such as Khayelitsha, there is an average infection rate of 33% (Essop, 2005:6). According to this assertion, one out of every three residents in this township may be HIV-positive.

### **2.7.3. The informal institution of subservience**

There is another informal institution which is very relevant to women’s disempowerment and the spread of AIDS and this involves the norms regarding the treatment and the role of women in society. If local norms dictate that a woman has to be subservient to a man, she will abide by these norms for fear of being shunned, not only by her partner, but also by the community (Kaufmann, 2004).

In a South African study examining gender attitudes and sexual violence-supportive beliefs in a sample of men and women at risk for HIV transmission, the researchers found that “Both men and women endorsed gender attitudes that represent traditional, submissive, and passive roles of women, with nearly all men and women stating that women should obey their husbands” (Kalichman & Simbayi, 2005).

When a man believes it is his right to have his lover obey him unquestioningly, “This obedience is often enforced through physical violence or the fear of it” (Usdin, 2003:50). Karen Dzumbira (as cited in Usdin, 2003:52) states that the lobola system “reinforces the idea that a woman is a man’s property and he can do with her what he wishes”. If a woman refuses to have sex without a condom, the price she has to pay could include abuse and loss of financial support. Thus, she may decide that the social, physical and economic costs are too high a price to pay and she may bow to the local norms of subservience (Kauffman, 2004).

## **2.8. CONCLUSION**

This chapter has discussed the social perceptions regarding HIV/AIDS and how formal and informal institutions dictate these perceptions. The role of language in social perceptions was discussed with particular reference to the mixed messages communicated by science, the media and government. The content of these messages as well as the way in which they have been conveyed contribute to the prevailing perceptions, attitudes and behaviour of people regarding HIV/AIDS.

In relation to social perceptions the issue of stigma and its effects were discussed and finally, the position of women and HIV/AIDS in relation to social, cultural and economic issues and constraints was referred to.

This literature review will be continued in the following chapter where the possible emotional effects of an HIV-positive diagnosis will be discussed.

**POSSIBLE REACTIONS TO AN HIV-POSITIVE DIAGNOSIS****3.1. INTRODUCTION TO THE CHAPTER**

This chapter continues the literature review and focusses on various ways in which people may react and respond when presented with an HIV-positive diagnosis. Coping could occur in the stages as discussed by Kubler-Ross, or depression, anxiety, stress or learned helplessness may ensue after such a diagnosis.

This chapter attempts to address the questions: How do women who are already burdened with the realities of poverty and of being subservient to a partner who has full control regarding their social and sexual interaction react when they are confronted with an HIV-positive diagnosis? How do they respond when they have limited education and information regarding HIV/AIDS and have knowledge of the stigma associated with an HIV-positive diagnosis? How are their reactions influenced by other forces such as knowing that there is no cure available and when they are assailed regularly with information concerning the ravages of AIDS and the increase in death rates attributed to the AIDS epidemic?

“Too often people who are informed that they have HIV, if they understand its significance, think they are being condemned to almost immediate death” (Mbuyo, 2000:65). He continues: “There are even occasional reports of suicide when people hear they have the virus, so great is their fear, anxiety, guilt, or shock at the finding” (Mbuyo, 2000:65).

Elizabeth Kubler-Ross’s (1970) coping stages, depression, anxiety, stress and helplessness are all possible ways in which people may react to an HIV-positive diagnosis.

Discussions around these issues follow.

### 3.2. KUBLER-ROSS'S COPING STAGES

Elizabeth Kubler-Ross (1970), in her lifelong work with terminally patients, identified five coping stages which are generally experienced after having been diagnosed as being terminally ill.

Kubler-Ross (op cit) avers that denial, or at least, partial denial is experienced by almost all terminally ill patients. This is usually a temporary defence when people just cannot believe what is happening to them. "Since in our unconscious mind we are all immortal, it is almost inconceivable for us to acknowledge that we, too, have to face death." This denial occurs not only when diagnosis takes place but also from time to time during the illness when the patient faces changing circumstances. Kubler-Ross feels that denial serves as a buffer after unexpected shocking news and allows the patient to collect himself/herself and to mobilise other, less radical defenses.

When the first stage of denial can no longer be maintained it is replaced by feelings of anger, rage, envy and resentment. Kubler-Ross (op cit) writes that the next question that is asked is "Why me?" This anger is displaced in all directions and is projected at random.

After the anger subsides, bargaining ensues. Most bargains are made with God and are attempts to postpone the inevitable. People may bargain for time to attend an important event such as a child's wedding or they may make promises to devote their lives to serving humanity if they are granted life.

When people can no longer deny their illness they will experience a great sense of loss and suffer from depression. Finally, they may experience acceptance which is a realistic evaluation of the situation and appropriate adaptation to the prevailing state of affairs (Kubler-Ross, op cit).

Kubler-Ross (op cit) includes depression as one of the stages people experience on their journey to acceptance of their terminally ill state. Depression can also be viewed as a mental health condition as described below.

### 3.3. DEPRESSION

Most people have, at times, experienced sadness, pessimism and a sense of hopelessness about issues in their lives. This state of depression is unpleasant, but it is usually self-limiting and when it has passed, one can move on again. This so-called state of 'normal' depression is usually the result of recent stressors experienced by the individual. Depression is characterised by sadness, fatigue, loss of interest in one's surroundings, neglect of the self, loss or gain of appetite, being agitated and experiencing sleep disturbances.

There is an inability to concentrate and suicidal thoughts may be present if the depression is severe, which can occur if a person is faced with a stressor which seems insurmountable. If the person perceives that her coping efforts will not remove the source of stress, then she will eventually give up and feelings of helplessness and hopelessness are seen as basic to depressive reactions (Carson, Butcher & Coleman, 1988).

In a Cape Town study of 149 recently diagnosed HIV/AIDS patients, psychiatric disorders were common: "the most prevalent psychiatric diagnosis was current depression" (Olley et al., 2003:930). The researchers found incidence in their study to be higher than that of other studies on HIV/AIDS patients in developed countries and considered that this may reflect higher levels of stress and stigmatisation experienced by HIV/AIDS patients in South Africa. The findings of this study accord with the findings mentioned here in that 19 of the 20 women interviewed reported symptoms of depression and two of them experienced suicidal ideation. (See Chapter Five for details of these findings).

A further emotional condition which may follow an HIV-positive diagnosis is that of anxiety which is outlined below.

### 3.4. ANXIETY

Sue et al (2003:127) aver that anxiety is a “fundamental human emotion” which can function as a warning signal to danger. However, intensive and overwhelming anxiety can lead to disturbances in functioning or cause significant stress (Sue et al., 2003). In anxiety disorders the predominant symptom is anxiety and avoidance is also nearly always present. These disorders can present as:

- Generalized anxiety, where excessive anxiety and worry prevails for a period of at least 6 months;
- Panic attacks characterised by episodes of apprehension and feelings of impending doom. Further symptoms are a racing pulse, constricted chest, choking, sweating and heart palpitations;
- Social phobia, where persistent fear of situations is experienced and avoidance responses are nearly always present;
- Post-traumatic stress, where a traumatic event is repeatedly re-experienced. Further symptoms include sleep disturbances, startle responses and an inability to concentrate. (Sue et al., op cit).

Olley et al (2005) conducted a study in South Africa to examine the prevalence of post-traumatic stress disorder (PTSD) in recently diagnosed HIV-positive patients. 105 females and 44 males comprised the total sample of 149 individuals. PTSD was found in 14.8% of the sample, representing 22 patients. The index trauma for 36% of these PTSD patients was knowledge of the diagnosis of HIV/AIDS. Twenty of the twenty-two patients were female. Furthermore, it was found that “PTSD was significantly associated with major depression, suicidality and social anxiety disorder in newly diagnosed HIV patients” (Olley et al., 2005:555).

Stress is another possible reaction to a traumatic event.

### 3.5. STRESS

Psychological stress refers to a certain type of relationship between the individual and the environment. "It is one in which the demands of any encounter tax or exceed the person's resources" (Cooper & Dewe, 2004:71). Appraisal is the process which links the person and the environment and when the transaction is appraised as being 'stressful,' coping processes come into play. Thus, both the person and the environment are key players in stress and coping (Cooper & Dewe, op cit). Individual perceptions of and reactions to environmental transactions are influenced by attitudes, beliefs, expectations and motives and all situations which require adjustment, whether they are positive or negative, are stressful. Hans Selye termed positive stress, 'eustress,' eg. a wedding, and negative stress, 'distress,' eg. a funeral. "The severity of stress is gauged by the degree of disruption in functioning that it entails" (Carson, Butcher & Coleman, 1988:141). This severity depends not only on the nature of the stressor, but also on the resources the individual has to cope with the stress, as well as how the stressor is perceived and evaluated by the person.

Dr. Hans Selye (as cited in Burns, 1988:4) coined the phrase "general adaptation syndrome" which divides stress into three stages, viz:

- The Alarm Stage, during which there are bodily changes associated with the emotions. Here one can either fight or take flight and people often revert to child-like behaviour over which there is little or no control.
- The Resistance Stage during which one recovers from the initial emotional state and tries to endure the stress. So much energy is expended on this activity, that one's general resistance is lowered.
- The Exhaustion Stage where, if the stress is overwhelming and the person cannot cope with it, exhaustion sets in.

Stress has emotional as well as physical effects and anxiety and depression are common.

Stress and emotions are interlinked, and where there is stress, there are also emotions (Lazarus, 1999). Lazarus (1999:37) adds the aspect of coping to this relationship and states that “stress, emotion, and coping, belong together and form a conceptual unit.”

Evidence suggests that positive family and social relationships can lessen the effects of stress and, conversely, the lack of personal or material support can weaken a person’s capacity to deal with stress.

Studies have implicated stress in incidents of strokes, heart disease and the suppression of the immune response (Sarafino,1994; Carpi,1996). It has been shown that chronic stress can lead to greater susceptibility to disease and to changes in an individual’s immune functioning. From a cognitive perspective, feelings of helplessness and hopelessness can have a negative impact on health decisions and therefore on one’s quality of life (Sue, Sue & Sue, 2003).

Feelings of helplessness are also a feature in the theory of learned helplessness which is described as follows.

### **3.6. LEARNED HELPLESSNESS**

Seligman coined the phrase “learned helplessness” to describe the reactions of animals and people when they are confronted with a situation which is uncontrollable and unchangeable (Peterson, Maier & Seligman, 1993).

#### **3.6.1. A definition of learned helplessness**

“Helplessness is the psychological state that frequently results when events are uncontrollable” (Seligman, 1975:9). An event is uncontrollable when we believe that we can do nothing about it and that nothing we do, matters. The outcome is thus independent of one’s voluntary responses (Seligman, 1975). Voluntary responses are those responses which can be modified by reward and punishment and are the sole concern of operant conditioning. “When an organism can make no operant response that controls an outcome, I will say the outcome is uncontrollable” (Seligman, 1975:12).

### **3.6.2. The criteria of learned helplessness**

There are three criteria by which to recognise this phenomenon:

- Learned helplessness exists when someone displays inappropriate passivity, thus failing to meet the demands of a situation where effective coping is possible.
- Learned helplessness follows as a result of being confronted with uncontrollable events. However, only if the person believes that the event is uncontrollable, can learned helplessness occur.
- Learned helplessness is mediated by certain cognitions acquired during exposure to uncontrollable events and inappropriately generalised to new situations (Peterson, Maier & Seligman, 1993).

Being exposed to an uncontrollable situation is not enough. One must believe that one is unable to control the situation and it is this expectation of uncontrollability which is the crucial determinant of helplessness (Seligman, 1975). The learned helplessness theory further proposes that the uncontrollability of a situation adds to the fear-arousing aspects of the situation and, if this continues, leads to depression. Furthermore, as well as depression, such negative emotions as anxiety and anger are also reported by those who experience uncontrollability (Peterson, Maier & Seligman, 1993). It is further hypothesized that helplessness is a potential mechanism for poor health. The more one experiences situations as uncontrollable, the more stressful this becomes and research shows that stressful life events can have a negative effect on one's health.

### **3.6.3. Early experiments**

During the mid-1960s, while carrying out experiments on dogs, regarding the relationship of fear conditioning to instrumental learning, Steven F. Maier, J. Bruce Overmier and Martin E.P. Seligman discovered that dogs who believed their experimental situation to be uncontrollable just gave up, lay down, whined and acted helplessly.

Although these findings applied to experiments with dogs, they were found, after various experiments with cats, rats, mice, birds, primates, fish, cockroaches and human beings, to typify what most species, including human beings, do when faced with an uncontrollable situation (Seligman, 1975). Subjects learn that they are helpless when faced with a situation which they consider to be uncontrollable.

Further human experiments conducted by Donald Hiroto, who replicated the laboratory findings on dogs in college students, and Glass and Singer found the same results. (Seligman, 1975). These studies showed that uncontrollability leads to a loss of motivation to respond adaptively to trauma. Seligman (1975:32) states: “I believe that what gets learned when the environment is uncontrollable has profound consequences for the entire repertoire of behaviour.” When a person learns that he/she is helpless in one situation, “much of the adaptive behavioural repertoire of that person may be undermined” (Seligman, 1975:36).

#### **3.6.4. Vicarious helplessness**

A person does not need to personally experience uncontrollable events for helplessness to ensue. People can learn to be helpless through the observation of others experiencing uncontrollable events and seeing the effects on those persons. “With the advent of the global television community, we can argue that more people are exposed to more uncontrollability than ever before in history” (Peterson, Maier & Seligman, 1993:112).

#### **3.6.5. Effects of learned helplessness**

When confronted with an uncontrollable situation, there are disturbances in:

- motivation, as responding requires an incentive such as an expectation that responding may succeed. If someone has learned that no amount or kind of responding will change the outcome, then response initiation decreases. Studies show that when a human being is faced with a situation he/she cannot control, motivation to respond is drastically reduced (Seligman, 1975).

- cognition, as learning that a response does not affect the outcome, makes it more difficult to learn later that responses produce that outcome. If people have a cognitive set where they believe that success and failure are independent of their own responses, they have “difficulty in learning that responses work” (Seligman, 1975:38).

- emotion, such as depression and anxiety. Seligman (1975) believes that fear is the dominant emotion when faced with an uncontrollable situation. If the situation can be controlled, the fear is reduced and may disappear, but if the situation cannot be controlled, fear will be replaced with depression. It has been shown that if there is only one experience with an uncontrollable situation, and if the emotional state is not reinforced, the negative effects will dissipate in time (Seligman, 1975). If, however, there are many experiences of uncontrollability, there is a chronic interference with initiating responses. Learned helplessness characterises some of the symptoms of depression, where the person is “slow to initiate responses, believes himself to be powerless and hopeless and sees his future as bleak” and this has come about as a result of having no control over outside events (Seligman, 1975:81).

In summary: “Laboratory experiments on learned helplessness produce three deficits:

- they undermine the motivation to respond;
- they retard the ability to learn that responding works;
- and they result in emotional disturbance, primarily depression and anxiety” (Seligman, 1975):

### **3.6.6. The Reformulated Learned Helplessness Hypothesis**

There were a number of limitations to the hypothesis and findings of the original studies on learned helplessness. The early studies did not distinguish between cases where outcomes are uncontrollable for all people (eg. a terminal illness) and cases where outcomes are uncontrollable only for some people (eg. a student who cannot solve maths problems, even though his/her classmates have no difficulty with this), i.e. universal vs. personal helplessness.

The studies also did not distinguish between when helplessness is general and when specific, or when chronic and when acute. The original learned helplessness theory as applied to people was reformulated in 1978 to include an assessment of a person's explanatory style, as "an individual's causal explanations for uncontrollable events influence reactions to them" (Peterson, Maier & Seligman, 1993:146). Further research was based on this reformulated model. When a person finds that s/he is helpless, s/he asks why? However, different people give differing causal explanations for the same situation and this leads them to react in different ways.

### **3.6.7. The Alleviation of Helplessness**

Various studies have been undertaken which show that immunization and therapy which "encourages people to see connections between their responses and outcomes," are means of combating the effects of helplessness (Peterson, Maier & Seligman, 1993:111). Immunization, as described by Seligman (1998:28) means that "Learning beforehand that responding matters actually prevents learned helplessness". Not only earlier, but also subsequent mastery learning can dissipate the effects of helplessness. The presence and persistence of helplessness depends on the permanence and pervasiveness of uncontrollability as perceived by the recipient. Therefore, measures which increase the levels of an individual's personal control can help to alleviate feelings of helplessness. Support systems can provide the means for this.

## **3.7. SUPPORT SYSTEMS**

Support systems are seen as "the existence or availability of people on whom we can rely, people who let us know that they care about, value, and love us" (Sarason et al. 1983:127). The individual's perception that there are people one can turn to in times of need and the satisfaction derived from this available support is important in assessing social support systems (Sarason et al., op cit).

Support groups may also serve the function of education. A study conducted in Limpopo Province found that support groups were an effective method of educating people about HIV/AIDS (Mabunda, 2004).

A further study by Gaede et al (2006) in KwaZulu-Natal investigated the relationship between social support and health behaviour in women living with HIV. A positive relationship was shown between social support and health behaviour. However, “receiving counselling together with membership of a support group showed stronger association with positive health behaviour than social support on its own” (Gaede et al, 2006). A significant change in health behaviour was a change in diet, but the study does not detail the changes.

### **3.8. CONCLUSION**

This chapter has focused on possible reactions of people when confronted with an HIV-positive diagnosis and has discussed various reactions and responses including depression, anxiety, stress and learned helplessness as well as the use of support systems as a means to alleviate feelings of helplessness.

The following chapter will describe the methodology used in gathering and analysing the data for this study.

University of Cape Town

## **CHAPTER 4            METHODOLOGY**

### **4.1.    INTRODUCTION TO THE CHAPTER**

This chapter presents the methodology employed in the study. The research approach and methods, sample selection, data collection, data analysis and limitations of this study are described and the issues of ethics and reflexivity are considered.

### **4.2.    RESEARCH APPROACH AND METHODS**

This study employs a qualitative approach and research methods which are exploratory and descriptive in nature and where the “actor’s perspective (the “insider” or “emic” view) is emphasized” (Babbie & Mouton, 2004:270). As the purpose of a qualitative study is to produce findings meaningful to the research problem, “participants’ natural language is used in order to come to a genuine understanding of their world” (de Vos, 2003:81). Thus, meaning, experience and perception is gleaned from the participant’s perspective rather than that of the researcher. Babbie & Mouton (2004:270) see this as attempting to “view the world through the eyes/perspective of the actors themselves”. To accomplish this “the researcher should be able to enter the subject’s ‘life world’ or ‘life setting’ ... and place himself in the shoes of the subject” (de Vos, 2003:273).

In any stressful situation people’s perceptions and experiences are affected by their personal circumstances, personality and coping resources and this study aims to interpret respondents’ ‘stories’ from within their unique contextual positions. The study is based on the view that there is no one truth, as multiple experiences of the same reality exist, and a qualitative approach creates the opportunity for gathering varying viewpoints. An interpretation of these various ‘stories’ broadens our knowledge of the perceptions and experiences of women after receiving an HIV-positive diagnosis. Furthermore, it also extends our knowledge of how support systems may be of positive benefit to these women.

### **4.3. SAMPLE SELECTION**

The study sample consisted of the volunteer leader, a focus group consisting of five facilitators and 20 women members of an HIV/AIDS support group located in Khayelitsha, a township in the Cape Peninsula. A Medical Officer of the City of Cape Town, as well as an officer from the Department of Social Services, also comprised part of the sample selection.

#### **4.3.1. Purposive sampling**

Purposive sampling, a type of non-probability sampling, was used in the selection of the volunteer leader of an HIV/AIDS support group in Khayelitsha. This person was chosen as she has been involved since the inception of the support group in 1995 and has specialised knowledge concerning the people who attend the group and their needs.

#### **4.3.2. Availability or Convenience Sampling**

Availability or convenience sampling, which is also a type of non-probability sampling, was used in the selection of the focus group of facilitators and the 20 women members of the HIV/AIDS support group in Khayelitsha. They were all in attendance on the days the researcher conducted interviews and they were willing to be interviewed and to answer questions put to them. Men and women attend the support group, but as this study focusses on women, only female members were requested to participate.

Given that this study makes use of convenience or availability sampling, care must be taken in generalising from the data to the total population (Babbie & Mouton, 2004).

#### **4.3.3. Key informants**

Key informants, viz. a City of Cape Town Medical Officer and an official from the Department of Social Services were selected by virtue of their position and knowledge. These individuals have specialised knowledge regarding the awarding of disability grants to HIV/AIDS patients and were available to be interviewed telephonically by the researcher.

#### **4.4. DATA COLLECTION**

Data was collected from the volunteer leader, a focus group of facilitators and 20 female members of an HIV/AIDS support group in Khayelitsha. Interviews were also conducted telephonically with a City of Cape Town Medical Officer and an official of the Department of Social Services.

##### **4.4.1. The Volunteer Leader – Individual Interview**

In order to gain a global picture regarding the behaviour, emotions and problems of women when they joined and first attended an HIV/AIDS support group, an in-depth, open interview was first conducted with the volunteer leader of a support group in Khayelitsha. Questions, based on the objectives outlined in Chapter 1, were asked to ascertain the volunteer leader's perception of how women coped with their HIV-positive diagnosis when they first joined the support group, what problems they experienced, what kind of support was offered to them and how this was perceived to be of benefit to the support group members (Appendix 1).

Issues perceived by the volunteer leader as impacting negatively on women after receiving an HIV-positive diagnosis were feelings of helplessness, fearfulness, lack of factual knowledge regarding HIV/AIDS, limited financial resources, experiences of stigmatisation and lack of support. She described the support group as offering support and acceptance, education and skills training and believed it held positive value for the group members.

##### **4.4.2. A Focus Group of Facilitators**

To confirm the issues emphasized by the volunteer leader the researcher then conducted an in-depth, open interview with a focus group of five facilitators of the HIV/AIDS support group in Khayelitsha. The purpose of this was to assist in developing questions for an interview schedule to be presented to a study sample of 20 women members from the support group.

The same questions asked of the volunteer leader, concerning the behaviour of women when they first joined the group, the problems faced by these women, what the support group offered them and how this was of benefit to them, were put to the focus group (Appendix 1).

The answers to these questions given by the focus group of facilitators, in conjunction with the answers given by the volunteer leader of the support group, formed the basis for the interview schedule for this study. (See Appendix 2)

#### **4.4.3. Support Group Participants – Individual Interviews**

In-depth individual interviews were conducted with the study sample of 20 women who currently attend an HIV/AIDS support group in Khayelitsha. An interview schedule (Appendix 2) was used but many of the questions were open-ended and the answers given to these were followed up with probing questions. The interviews were conducted in a private room in the clinic which, although quiet, was rather cold and a heater was brought in. Interviews always took place in the presence of a facilitator of the support group who also doubled as an interpreter when necessary. Interviews, which varied in length from 30 to 60 minutes, were recorded by the researcher in longhand as problems were experienced with the tape recorder.

#### **4.4.4. A City of Cape Town Medical Officer – A Telephone Interview**

A Medical Officer of the City of Cape Town was telephonically interviewed regarding policy on ARV treatment and the awarding of disability grants to AIDS patients.

#### **4.4.5. An Official of the Department of Social Services – A Telephone Interview**

An official of the Department of Social Services was interviewed telephonically to establish the policy regarding the awarding of disability grants for AIDS patients. He referred the researcher to the government website which was visited for specific information concerning the granting of disability grants.

## **4.5. DATA ANALYSIS**

“Data analysis is the process of bringing order, structure and meaning to the mass of collected data” (de Vos, 2004:339). The researcher followed the various steps in the data analysis process as listed by De Vos (2004:340), who points out that these steps, although presented linearly also move in a spiral. They are: the collection and recording of data; the managing of this data; reading and writing memos; the description, classification and interpretation and finally, the representation of this data.

### **4.5.1. The collection and recording of data**

Erlandson et al (1993) write that in qualitative research, data analysis begins during data collection at the research site and continues between site visits and after data collection completion. “A qualitative study involves an inseparable relationship between data collection and data analysis” (de Vos, 2003:341). In this study data analysis began with the first interview conducted with the volunteer leader of the HIV/AIDS support group and continued away from the site when emerging issues were documented. As explained earlier, an interview with a focus group of facilitators of the same HIV/AIDS support group followed, posing the same questions as set to the volunteer leader (Appendix 1). Confirmation of the major issues emphasised by the volunteer leader led to the amendment of an interview schedule for the support group participants (Appendix 2). This was tested by means of a pilot study with 2 support group members, which led to further refinements of the questionnaire.

### **4.5.2. The management of data**

The management of data analysis takes place away from the site of research and de Vos (2003:343) sees it as the “first loop in the spiral”. As interviews had been recorded in longhand, these were summarised, typed and printed out for greater efficiency of data analysis.

### **4.5.3. Reading and writing memos**

The answers to the questionnaires were read in their entirety many times over to gain a sense of the interview as a whole and to become familiar with the data. While reading, notes were made of ideas and thoughts occurring to the researcher.

### **4.5.4. Description, classification and interpretation**

De Vos (2003:344) writes that “category formation represents the heart of qualitative data analysis”. Creswell (1998) avers that, in classifying, the researcher looks for categories or themes. In this study, salient and recurring themes that emerged from the qualitative data which were gathered, regarding the reactions and behaviour of women after receiving an HIV-positive diagnosis, were identified. Similarly, categories of information were developed concerning the extent of knowledge of HIV/AIDS, the availability of financial resources, the issue of stigma and if and how the support systems which the respondents made use of to assist them in coping, were of benefit to them. “Interpretation involves making sense of the data” (de Vos, 2003:344) and the researcher had to critically evaluate the patterns that emerged and consider alternative explanations for this data. During this stage the literature reviewed for the study provided useful concepts and theories.

### **4.5.5. Representation of this data**

The findings, as interpreted by the researcher, were formulated and these are presented in Chapter 5. To maintain anonymity, each respondent was given a number, e.g. S1 (Sample 1), by which they are identified. The presentation makes use of a few tables, as well as quotes and stories to illustrate and explain the experiences of these women.

## **4.6. LIMITATIONS OF THE STUDY**

### **4.6.1. The Respondents’ Emotional Responses**

The women who were interviewed were all HIV-positive and the questions that were asked of them evoked some very painful emotions.

They were asked to go back in time to reveal their reactions and feelings on receiving their HIV-positive diagnosis and had to relive a very unhappy period in their lives.

Empathy and acceptance by the researcher were of paramount importance to convey understanding of the respondents' feelings and to facilitate as full a representation of data as possible but it is possible that the emotions experienced by the respondents led to the omission of anxiety-provoking information.

#### **4.6.2. Language Issues**

Language presented a challenge in that the respondents were all Xhosa-speaking and the women were asked to participate in an interview with an English-speaking researcher who had no knowledge of their language. At times this was a deterrent to gaining pertinent information. Many of the respondents did not speak English and an interpreter therefore had to be used. Of those interviewees who could engage in the interview in English, many had a poor command of the English language and their responses were thus fairly superficial. This factor may have limited the data collected.

#### **4.6.3. An Attending Facilitator often acting as Interpreter**

Each individual interview was attended by a facilitator who, when necessary, acted as the interpreter as well. This facilitator/interpreter often had an even poorer command of the English language than those that she was trying to assist. It was therefore difficult for the respondents, as well as the interpreter, to render their answers intelligible to the researcher who could not help them at all in this respect, as she has no knowledge of the Xhosa language.

After being asked a question, the interpreter and the respondent would talk freely and at length in Xhosa but the interviewer would be given an answer of a few words only and often the interpreter struggled to express herself in English. It was obvious that the questions elicited a response which was far more comprehensive than that which was finally offered to the interviewer.

In addition, it should be noted that the facilitators are trained volunteers who are paid for their work at the support groups and they therefore have a vested interest in knowing what is asked and answered during the interviews. It is possible that respondents may have said what they thought the facilitators would like to hear. For instance, education on HIV/AIDS decrees that condom use is of prime importance in preventing the disease as well as being re-infected and respondents said they had learnt to use condoms. However, some of the respondents had had children since being diagnosed and, on further questioning, it appeared that condom use was not universal.

Also, respondents were unanimous in their praise of the support group. However, they attend the support group for assistance and they may have omitted negative information for fear of offending the facilitator. Furthermore, interviewees may not have wanted to divulge certain information as they may have wished to keep some matters private from the facilitator.

#### **4.6.4. Perceptions of the Interviewer**

The interviewer is an older, white, middle-class female and was unable to communicate with the respondents in their own language. It was felt that the informants would not necessarily react positively to being questioned by an outsider who obviously did not share the same lifestyle that they did and who would not be familiar with the hardships and difficulties which they experience on a daily basis.

It is possible that information was withheld because of these factors of difference. The use of empathy and acceptance by the researcher may, however, have eased the difficulties inherent in the social, cultural, economic and educational divide between interviewer and interviewee.

#### **4.6.5. Written Data Collection**

The researcher recorded all the data in longhand and this could have presented an obstacle in capturing certain emotional nuances and detailed information.

#### **4.7. ETHICAL CONSIDERATIONS**

Permission for the study to be conducted was obtained from the Support Group Organisation from which the interview sample was drawn. The significance and aims of the study was explained to the participants and informed consent was obtained from each respondent. Although it is known that the participants are attached to an HIV/AIDS Support Group in Khayelitsha, the anonymity of individual respondents has been maintained and any information that they may not have wished to be used, was excluded. It was stressed that participation in the study was voluntary and withdrawal could take place at any time during the interviewing process without consequences to members' participation in other facilities.

Painful and emotional issues were often broached during the interviews and the researcher approached these issues with sensitivity. Care was also taken to ensure that the respondents did not leave the session in a state of distress. Interviewees were referred for further support and counselling if this was needed.

A copy of the thesis will be given to the Support Group and participants can have access to a summarised copy of the findings if they so wish.

#### **4.8. REFLEXIVITY**

De Vos (1998:369) sees reflexivity as "the ability to formulate an integrated understanding of one's own cognitive world, especially understanding one's influence or role in a set of human relations". When interviewing the respondents, the researcher became involved in their lives and, as the subject of HIV/AIDS can be highly emotive when one has been diagnosed HIV-positive and is living with this disease which is currently seen as terminal, it was difficult not to be moved by their stories.

The researcher acknowledges that objectivity had to prevail, but the sheer hardships of many of the respondents' lives often led to feelings of helplessness within the interviewer, which mirrored those of the interviewees.

The researcher therefore had to be constantly aware of the feelings that were being aroused and needed to consciously contain these emotions while retaining the quality of empathy.

#### **4.9. CONCLUSION**

This chapter described the qualitative approach used in this study. By means of the research approaches and methods used, the researcher gained an 'inside view' of the perceptions and experiences of women after receiving an HIV-positive diagnosis.

The following chapter will present the findings of this study and discussions based upon these findings.

University of Cape Town

### 5.1. INTRODUCTION TO THE CHAPTER

This chapter presents the findings of the study and discussions related to these findings. These results were obtained from an analysis of the data collected during interviews conducted with the volunteer leader, the focus group of facilitators and the women from the support group of women diagnosed HIV-positive, as well as a City of Cape Town Medical Officer and an official from the Department of Social Services. A thematic content analysis highlighted recurrent themes in the data which are recorded in this chapter.

The results and discussions regarding each of the five objectives of this study, as listed in Chapter 1, are presented in turn.

### 5.2. OBJECTIVE 1: TO DETERMINE THE REACTIONS AND BEHAVIOUR OF WOMEN AFTER BEING DIAGNOSED AS HIV-POSITIVE.

The analysis of the data obtained from the research identified the recurrent themes of belief of uncontrollability, feelings of helplessness, anxiety and depression and lack of action. Table 1 shows the number of respondents who experienced these feelings and behaviour. As will be apparent in the forthcoming discussions, some of these themes overlap to some extent.

*Table 1 Recurrent themes identified in the study*

Total 20

Belief of Uncontrollability	Feelings of Helplessness	Anxiety	Depression	Lack of Action
20	19	19	19	19

As shown in Table 1, all of the respondents believed that their situation was uncontrollable and all but one of the respondents experienced feelings of helplessness, anxiety and depression and displayed a lack of action..

### **5.2.1. Belief of Uncontrollability**

After being diagnosed HIV-positive all 20 respondents were convinced that they were going to die and many of them believed this death to be imminent. Furthermore, they believed that this death would be most unpleasant and there was nothing they could do to change their situation. Although it is true that there is no cure for HIV/AIDS and it can therefore be seen as a terminal illness, there are ways in which one may prolong the asymptomatic phase of this disease and consequently one's lifespan and there is medication which reduces the viral load. However, these women implicitly believed that they were totally unable to exercise any control whatsoever over their condition.

S10 had watched the T.V. programmes featuring Nkosi Johnson, a young boy who had died of AIDS, and she knew that there was no cure for HIV/AIDS. She also knew that he had become very ill and then had died, so she was convinced that she would suffer a similar fate and that there was nothing that she could do about it. This fatalistic belief was repeated by most of the other respondents, who believed they were going to die because they said they had learnt what had happened to other HIV-positive individuals from programmes on T.V. and the radio or from what they had been told by their friends, family, community members and others, or read in the media.

Lupton (1994) states that the entertainment and news mass media play an important role in the development of shared cultural meaning regarding AIDS. It is suggested that sensationalist media reporting which concentrates on the Grim Reaper, Death Voyeurism aspects of the disease, almost to the exclusion of reports of positivity where people live productive and healthy lives with HIV, have an impact on people's belief systems regarding this disease. Unfortunately, these fatalistic communications are then inculcated into people's reservoirs of knowledge of HIV/AIDS and they see no life after an HIV-positive diagnosis, but only death.

### 5.2.2. Feelings of Helplessness

Nineteen of the respondents believed that, once they were diagnosed HIV-positive, they were helpless and that there was nothing they could do to help themselves and therefore they did nothing.

S2 said: “I was helpless” and, similarly, the other respondents felt totally helpless and just ‘gave up’ as they were convinced that nothing they could do would alter their situation. The focus group of facilitators and the volunteer leader confirmed that when HIV-positive people first joined the support group they suffered from feelings of hopelessness and helplessness and they believed that there was nothing they could do to alleviate their situation.

This cognition of helplessness prevailed, even though the City of Cape Town Medical Officer informed the researcher that people were given information and counselling when diagnosed HIV-positive. Although sixteen of the twenty interviewees said they had been given pamphlets and other information at the counselling site, this did not appear to have tempered their feelings of helplessness. One of the interviewees said she was told she would not die but she knew this to be a lie and therefore she did not believe anything else the counsellor told her. This suggests that counselling involves communicating a quite complex message regarding HIV/AIDS and its consequences.

These feelings appear similar to those described in the theory of learned helplessness as described by Seligman (1975). He states that “Helplessness is the psychological state that frequently results when events are uncontrollable” (Seligman, 1975:9). All but one of the respondents in this study had learnt, by various means, that death accompanies an HIV-positive diagnosis. While their factual knowledge of HIV/AIDS was minimal, they knew that they were to become very ill, believed that they were going to die and were convinced that there was nothing they could do to help themselves. Therefore a sense of helplessness and hopelessness prevailed. Peterson, Maier & Seligman (1993) state that only if a person believes that an event is uncontrollable a state of learned helplessness can occur.

In this study, all but one of the interviewees believed implicitly that there was nothing they could do regarding their situation and the data suggests that a lack of factual knowledge regarding HIV/AIDS contributes to this understanding and ultimately leads to a sense of helplessness regarding the disease.

### **5.2.3. Anxiety**

Nineteen of the respondents expressed feelings of extreme anxiety after being diagnosed as being HIV-positive. They believed that they were going to die and most of them expected death to be imminent. This spectre of death made them fearful and anxious. They also believed that they would become very ill and this too caused great anxiety as they had seen or heard of others' suffering.

S16 said her heart beat so fast, it felt as if it was going to jump right out of her chest. She became physically agitated and very anxious, knowing that she was going to die.

S13 was worried about her children and her mother and she did not know how they would manage to survive if she died.

S2 worried about who would pay for her funeral. She reported that she had approached a funeral parlour to enquire about a burial policy. There she was told that, as she was HIV-positive, her premium would be increased. As she could not afford to pay the loaded premium, she still does not have a burial policy and this is very worrying for her.

If a funeral is important to a family and there is no policy and no money to pay for the burial, what implications does this have, not only for the terminally ill person, but also for the family? The issue of the importance of funerals for the deceased and how this cost is borne could bear further exploration.

When S8 received her HIV-positive diagnosis, she thought that she was going to die immediately. So she started counting the minutes, the hours and then the days that she was still alive. The days became weeks, then months and finally a year had passed, but the anxiety continued until she joined a support group and met members who were still alive after ten years.

Peterson, Maier & Seligman (1993) write that negative emotions such as anxiety are experienced by those who believe that their situation is uncontrollable. As discussed in Chapter Two, the death experience, as frequently described and portrayed in the mass media, is fear inducing.

#### **5.2.4. Depression**

In this study it was found that depression was subjectively experienced by all but one of the interviewees. Respondents described this depression as a state including sadness, crying, listlessness, loss of interest in everything, sleeping problems and, as discussed earlier in this chapter, feelings of helplessness and hopelessness. One of the respondents was hospitalised for depression and two of the interviewees reported that they had contemplated suicide.

S3 said that she had been extremely depressed for 4 years and had wanted to kill herself.

S11 'cried her heart out' when she heard the news and became very depressed. This lasted for many months and she seriously and often contemplated suicide as she knew that she was going to die anyway and that it would not be a pleasant death. She felt she would experience an easier death if she committed suicide.

S1 said that she was very depressed and could not do anything for at least six months. She cried continuously and spent a lot of time in bed. When she was out of bed she closed her bedroom door and kept to herself. She did not want anyone near her. Every time she heard something concerning HIV/AIDS on the T.V. or radio, she cried and became even more depressed.

The respondents' state of depression and anxiety lasted from between a few months to as long as four years and, according to many of the interviewees, this depression and anxiety only abated after they joined an HIV/AIDS support group. The focus group of facilitators and the volunteer leader confirmed that people who came to the support group invariably suffered from anxiety and depression at the time of joining and that they were very fearful of dying.

Seligman (1975) believes that fear is the dominant emotion when faced with an uncontrollable situation and if this continues, fear will lead to depression. This appears to be the processes that occurred with the respondents.

#### **5.2.5. Lack of action**

Nineteen of the interviewees said they were 'shocked' when told that they were HIV-positive and because they believed there was nothing they could do to change their situation, they did nothing at all. This meant that they just 'gave up'.

S1 and S15 both stated that they were unable to do anything at all for many months. They spent most of their time in bed and when they did get up, they kept to themselves and stayed away from others. They spent a lot of their time alone, behind closed doors.

S14 said: "I wrapped my blanket around myself and lay in bed for most of the time doing nothing at all. I did not go out, I just did nothing."

Peterson, Maier & Seligman (1993) state that passivity is one of the three criteria by which one may recognise the phenomenon of learned helplessness. The majority of respondents in this study said that they did nothing after being diagnosed HIV-positive as they believed there was nothing that they could do. They also reported that this state of inaction caused them great distress.

Because of their lack of action they failed to seek factual information regarding their condition or immediate assistance as they did not believe that there was anything they could do to help themselves.

Continued passivity after receiving an HIV-positive diagnosis is unfortunate as there are various tasks, activities and actions which need to be attended to immediately if one is infected with HIV. For example, there is the aspect of 'safe sex' to be addressed in order to prevent transmission of one's own infection as well as to prevent reinfection. There is also the need to determine whether or not one's partner has been infected and, if one has children, to find out if they are HIV-negative or positive, so that the necessary steps may be taken to protect their health.

Factual information regarding the disease should also be sought immediately so that measures may be taken to optimise one's chances for prolonged health. In this regard Whiteside & Sunter (2000) write of the need for a healthy diet, minimizing stress and keeping free of other diseases so as to optimise the duration of the asymptomatic phase 2. Also of vital importance is the utilisation of support systems such as family or clinics which may be helpful for one's emotional health. Periods of inaction after receiving an HIV-positive diagnosis can place one's chance for health in jeopardy and can have serious negative consequences. Because of the nature of HIV it is important that people strive to seek support and information as soon as possible so as to optimise control over their situation, thereby enhancing their chances of leading a longer and healthier life.

### **5.3. OBJECTIVE 2: TO DETERMINE THE EXTENT OF THE WOMEN'S KNOWLEDGE REGARDING HIV/AIDS AND HOW THIS INFLUENCED THEIR REACTIONS AFTER BEING DIAGNOSED AS HIV-POSITIVE.**

An analysis of the answers to the questions concerning this objective suggests that the communication of information and confusing advice regarding HIV/AIDS influences the knowledge that patients have of this disease.

#### **5.3.1. General knowledge regarding HIV/AIDS**

The table below shows the number of respondents who said they had no factual knowledge and those who had only rudimentary knowledge of HIV/AIDS at the time of their diagnosis. It also states the number of interviewees who had received information and literature at pre-and post counselling sessions when testing for HIV.

Table 2 Knowledge regarding HIV/AIDS

Total 20

No factual knowledge	Rudimentary knowledge	Information received at pre- and post-counselling for HIV
14	3	16

Fourteen of the respondents said they knew nothing about HIV/AIDS before being diagnosed as HIV-positive and three interviewees had only rudimentary knowledge which consisted of knowing that they had to use condoms to prevent HIV infection. Sixteen of the respondents had received information and pamphlets on HIV/AIDS when presenting for testing but they reported that they had not read the literature. Of the fourteen women who said they had no knowledge regarding HIV/AIDS, five had a family member and two had neighbours who were either HIV-positive or who had AIDS related illnesses. Although the respondents said they had little or no factual knowledge regarding HIV/AIDS, they had learned from the mass media, family, friends and community members that if you were diagnosed HIV-positive you would die and most of them believed this death to be imminent. As indicated earlier in this chapter, they also believed that there was nothing they could do to change their situation and this was generalised to a belief that there was nothing they could do to help themselves, which culminated in feelings of helplessness.

The volunteer leader and the focus group of facilitators said that when members first join the support group they are very ignorant and they know very little about HIV/AIDS. This lack of information as well as the inaccurate knowledge which they do have, leads them to incorrectly believe that there is nothing they can do to help themselves when they are diagnosed as being HIV-positive. Furthermore, it would appear that the information or misinformation which they have gained influences their behaviour and emotions and contributes to negative feelings of helplessness, anxiety and depression when confronted with an HIV-positive diagnosis.

### 5.3.2. Knowledge regarding ARV treatment

In South Africa a CD4 cell count of below 200 qualifies an HIV/AIDS patient for receiving antiretroviral drug treatment although the acceptance of this treatment is not obligatory. Three of the interviewees, one of whom was raped, reported having received antiretroviral treatment. However, two of the respondents refused the treatment which they believe to be toxic.

S1 reported that her CD4 cell count is only 154, but she is scared of treatment and S17 refused mother-to-child-transmission (MTCT) drugs for the same reason. They both believed that it was not safe to take these drugs.

Chapter Two refers to the misinformed messages of South Africa's Health Minister making a contribution to the confusion regarding treatment for HIV/AIDS patients. It is suggested that these may have contributed to the lack of trust and compliance amongst the populace. However, this issue was not explored in depth in this study.

### 5.4. OBJECTIVE 3: TO DESCRIBE THE EFFECT OF STIGMA ON HIV-POSITIVE WOMEN

Table 3 Experiences of stigma

Total 20

Number of respondents Stigmatised	Number of respondents rejected by partners	Number of respondents experiencing name-calling
18	15	18

Eighteen of the twenty interviewees reported that they had suffered from some form of stigma. The only respondent who said she had not experienced helplessness, passivity, depression and anxiety, said she had also suffered the effects of stigma. Of the two interviewees who had not experienced stigma, one woman said her boyfriend had supported and stayed with her and they have subsequently had another child. Her family have also been supportive.

The other respondent who did not experience stigma was a woman who had been raped and her family had also stood by her and given her their support. However, all the other respondents said that, to add to their feelings of depression and anxiety, they had all suffered from some form of stigma or rejection. Because of this, many of them have become very selective about to whom they disclose their status.

The stigma experienced by the respondents was expressed in the following ways:

#### **5.4.1. Rejection by spouses/partners**

Fifteen of the respondents said that their husbands or boyfriends had left them after they had been diagnosed as HIV-positive and because of this many of them have not told anyone else about their status.

S13 said that when she informed her boyfriend, he went out on a drinking spree and told everyone about her positive status and then he left her. People became very nasty to her and called her names and because of this she stayed away from others and became very isolated.

S19 said her husband left her when she was diagnosed HIV-positive but he returned when he too became ill and she had to nurse him until his death. She had no money and had to sell whatever she had in order to survive.

Fifteen women had lost their partners after disclosing their HIV-positive status to them. The men had bad-mouthed them, blaming the women for the problem and had then left as they refused to live with an HIV-positive partner. These women had therefore lost their sources of support, both emotional and financial as a result of this stigma.

One of the respondents did not join a support group for two years as a result of being stigmatised and rejected by her boyfriend. Because of his behaviour she believed that she would be similarly rejected if she reached out to others.

#### **5.4.2. Family rejection and abuse**

S3 said that when she told her mother that she was HIV-positive, she was verbally abused and rejected and told never to return to her family home.

S18 told how, while she was in hospital having her baby, her family had burnt all her belongings and had refused to have her back in their home. Her boyfriend also left her and, as she had nowhere to stay, she moved from partner to partner and drank to excess.

#### **5.4.3. Being shunned**

S17 said that when people found out that she was HIV-positive they were scared that she would infect them and they stayed away from her. This hurt her so much that she kept away from others as much as possible.

#### **5.4.4. Name calling**

All of the eighteen respondents who said they had suffered from stigma, had experienced discrimination from others and most of them had been called nasty names when they had disclosed their HIV-positive status.

S8's boyfriend swore at her and ran away and people called her names and mocked her. This response led to her not joining a support group for two years as she believed that she would automatically be rejected by everyone who knew her positive status.

S3 stated that she had been called a "baboon" when she disclosed her HIV status because the HIV virus is said to come from baboons. Because of this she does not want anyone to know that she is HIV-positive.

#### **5.4.5. Effects of stigma**

HIV/AIDS is not only a debilitating diagnosis for women but it also disempowers them as it leads to stigmatisation by many segments of the community and thus loss of self-esteem. Rohleder & Gibson (2005:3) state that HIV-positive women “face additional stigma of being perceived as deviant, dirty and damaged”. In this study most of the respondents were subjected to name calling, as they were seen to be the ‘shameful other’, the ‘contaminated’, the ‘bad’ and even the ‘baboon people’. These various experiences of stigmatization, discrimination and rejection have led to most of the respondents becoming secretive regarding their HIV-positive status so that they would not suffer the scorn and abuse of others.

The majority of the respondents, the focus group of facilitators and the volunteer leader all agree that stigma remains a major problem which not only exacerbates possible feelings of helplessness experienced after an HIV-positive diagnosis, but it also prevents or delays the quest for assistance and information. Parker & Aggleton (2002:5) maintain that stigma and discrimination are “the greatest barriers to preventing further infections, providing adequate care, support and treatment and alleviating impact.”

#### **5.5. OBJECTIVE 4: TO EXPLORE THE RESPONDENTS’ FINANCIAL RESOURCES WHICH COULD EITHER FACILITATE OR MILITATE AGAINST THE LEADING OF AN OPTIMALLY HEALTHY LIFESTYLE.**

The lack of financial resources plays a significant role in the lives of all of the respondents. Only four of the interviewees have ever had prior employment; two were still working at the time of the study. This means that the majority of the respondents are currently unemployed and most have never had employment and thus have been totally dependent for their livelihood on either their parents, family members, husbands or boyfriends or government grants. Of the two respondents who are currently employed, one respondent is a facilitator with the HIV/AIDS support group in Khayelitsha and earns a salary equivalent to a monthly grant, and the other works as a paid community volunteer for a wage of R500-00 per month. The two respondents who had previous employment were domestic workers at some stage but they were currently unemployed.

The table below presents the income presently available to the 20 support group members who were interviewed.

*Table 4 Financial resources*

Total 20

Number of Respondents	Income	Comments
1	No income	She begs for food
1	Dependent	On her husband who receives a disability grant
1	Dependent	On her grandmother who receives an old-age pension
1	Dependent	On her boyfriend
2	Employed	They work as paid volunteers, one earning R500-00 and the other R820-00 per month.
1	Temporary disability grant	This could be discontinued as her CD4 count is increasing
13	Child grants for 1 to 3 children	Three of these women also receive disability grants and one supplements her income by about R80-00 per month doing beadwork.

### 5.5.1. Special government grants for HIV/AIDS

The findings related to government grants and their influence on both health and poverty are examined. The information regarding grants was provided by a City of Cape Town Medical Officer, the Official for the Department of Social Welfare and the [www.capegateway.gov.za](http://www.capegateway.gov.za) website.

Although there are no special grants for people with HIV/AIDS, the national norm is that, a disability grant will be given if the patient is seen as being in Stage 4 of the HIV/AIDS disease with a CD4 count of approximately 50 or less and would thus be unable to work and only have about one year to live without antiretroviral treatment.

In addition, if a person is in Stage 3 and has a higher CD4 cell count but also suffers from additional diseases such as tuberculosis, which has made employment impossible, a disability grant is given. In such cases grants may be given only temporarily, e.g. for six months or a year, until such time as the patient's physical health improves and he/she is once again able to work. Patients are given grants only if they are too ill to work as with a CD4 count of 200 some people are still well enough to be employed. What is not taken into account in this equation is that there are few jobs for unskilled workers, which typifies the sample under discussion. As was stated earlier in this chapter, only 4 of the 20 respondents had ever been employed.

The abovementioned website states that a permanent disability grant will be given if the disability is permanent. However, if the disability, which is assessed by a doctor in a medical examination, is seen as only lasting for between six months and a year, a temporary disability grant will be issued. To qualify for this grant, a single person's income has to be less than R1686 per month and you cannot receive the grant if you refuse to undergo medical treatment. This was confirmed by the official of the Department of Social Welfare. This arrangement poses a dilemma, as you may become too ill to work with a low CD4 cell count, but if you receive antiretroviral treatment which lowers the viral load, your CD4 count will improve and the grant will be discontinued if you are deemed well enough to be employed.

S2 said that she has been given a grant for 6 months only and, as a result of antiretroviral medication her count has now increased to 231. If it continues to rise, her grant will definitely be discontinued when she returns to the hospital for a check-up. She does not know what she will do when this happens. Her youngest child is fifteen, so she cannot apply for child support as a child support grant is only available for a child to the age of fourteen. Even though she sells chicken feed for extra money, the returns are low and not enough to support her and her child.

S5 also received a temporary disability grant, as her CD4 cell count was low and she was ill, but her CD4 count has since increased and the grant was discontinued. Fortunately, she has become a facilitator at the HIV/AIDS support group for which she is paid a wage equivalent to that of a monthly grant.

S3 lives with her 'chommie' as she calls her girlfriend and neither of them have any source of income. She says they both attend the support group and, apart from the meal they receive there, they also each receive a food parcel every month. As this does not last for very long, they have taken to begging for food. She has not been able to secure any employment and as her CD4 count is still above 300 she also cannot apply for financial assistance in the form of a disability grant. She is therefore destitute and has to rely on others for her survival.

### **5.5.2. The effects of disability grant availability**

Despite the current policy, it would appear that the issuing of disability grants does not occur uniformly. Some interviewees said they received a disability grant when their CD4 cell count was just below 200 and it would seem that there is no clear guideline on the level of the CD4 cell count in determining whether or not the doctor awards the grant. The main criterion in extending a disability grant appears to be the ability or inability of the individual to work.

Cognisance is not taken of the fact that there are no or very few jobs available for unskilled workers; the unemployment rate is 30% as at September 2001 (Statistics South Africa, 2001). It is also not recognised that this grant may be the only available financial resource for this person. Therefore if the grant is removed, the person may be destitute. This issue raises questions as to whether one is compelled to take antiretroviral drugs when receiving a grant. If one is ill one receives a grant but if one recovers, the grant is removed.

If somebody has no income and no means of obtaining an income it may be expedient to practice non-compliant drug taking and thus remain ill. Whichever choice one makes is a terminal one, as losing the grant means starvation today, while keeping the grant keeps one alive today to die tomorrow.

The issue of a lack of financial resources in creating a sense of helplessness and hopelessness is very relevant in a township such as Khayelitsha which is reported to have the highest prevalence of both poverty and HIV in the Western Cape (Shabodien, 2003).

The feelings of helplessness experienced by the respondents may have been exacerbated by their social position, but it is also possible that the precarious financial position of these women led to a sense of despair and uncontrollability concerning their situation and consequent display of helplessness.

### **5.5.3. Child support grants**

Given the precarious financial positions of the women included in the study, the only means of financial support is that of government grants, either in the form of child support or a disability grant because of their illness. Six of the interviewees reported that they have had babies since their HIV-positive diagnosis. Most of the respondents had also said that they used condoms but when probed, conceded that they did not. A child support grant could therefore be viewed as a viable option for financial support for some women, as this may be their only means of income. The focus group of facilitators agreed that this was a possibility and said that people had to survive. If these women have a future life span of approximately a decade, they will be creating young orphans if they die. However, when people have no immediate means to feed themselves and their families for the moment, the ramifications of leaving orphaned children behind some time in the future would not seem so dire.

## **5.6. OBJECTIVE 5: TO DISCOVER THE NATURE OF SUPPORT SYSTEMS WHICH ARE HELPFUL AND BENEFICIAL TO HIV-POSITIVE WOMEN**

As reported earlier in this chapter, all the respondents in the sample group, except one, had suffered from feelings of helplessness and hopelessness, depression and anxiety and they had remained inactive with regard to coping with their situation as they did not believe that there was anything that they could do to help themselves. This situation had varied in time from a few months to a period of four years, as experienced by one interviewee. The focus group of facilitators and the volunteer leader confirmed that these were the emotions and behaviour people displayed when they first joined and arrived at the support group. However, they averred that membership of the support group alleviated members' negative emotions and assisted them in dealing more positively with their illness.

All twenty respondents agreed that joining the HIV/AIDS support group had been helpful, and receiving education, acceptance and support, skills training and material resources had proved beneficial for them.

### **5.6.1. Education**

The focus group of facilitators and the volunteer leader said that the majority of the members were very ignorant of facts concerning HIV/AIDS when they first joined.

This lack of salient information lead to a great deal of distress as people believed that they were unable to do anything to help themselves once they were diagnosed HIV-positive.

#### **5.6.1.1. Education regarding HIV/AIDS**

All of the respondents said they had gained a great deal of information regarding HIV/AIDS at the support group meetings. They said that this had helped them to realize that they could cope more positively regarding their HIV-positive status. A few members have been with the support group since the early 1990s and, although most of the respondents believed that their death was imminent once they were diagnosed positive, they were given renewed hope of a longer lifespan when they met people at the group who were still well and fully functioning after many years.

#### **5.6.1.2. Education regarding nutrition**

Support group members said they were also taught how to eat healthily. A garden has been cultivated in the grounds of the clinic where peanuts and vegetables are grown for members' consumption and where people are also taught how to tend their own gardens. However, it appears that for financial reasons none of the sample of women interviewed are able to maintain a diet which may promote optimal health.

Information from the volunteer leader and the focus group of facilitators suggests that this tenuous financial position can be generalised to all of the support group members.

### 5.6.1.3. Education regarding prevention

A greater difficulty arises with education regarding prevention of HIV transmission. During the interviews, when the researcher asked what the respondents were doing to promote the prevention of HIV, most of them replied that they were using condoms. However, six respondents had borne children since being diagnosed and when this was mentioned to these respondents, they conceded that they did not use condoms.

This issue was raised with the focus group of facilitators and the volunteer leader who said that, although condom use was advocated, this was often not a viable proposition for the women of the group as their partners usually refused to comply with their requests. They maintained that the women were often subservient to and dependent on partners for their livelihood. Education regarding prevention is therefore not sufficient to change behaviour, as social factors have to be taken into consideration. Irwin, Millen & Fallows (2003:37) write that “insist on safe sex” AIDS prevention messages “do not square with a social critique of poverty, inequality, racism, gender discrimination, and other structural factors.....”

### 5.6.1.4. Effects of education

The respondents all said that they had gained a lot of knowledge in the support group regarding HIV/AIDS and this had helped them tremendously as they now knew that they would not die immediately and they knew that they could stay healthy for longer. It was maintained that this knowledge had also alleviated the anxiety and depression which they suffered from when they first joined the group.

## 5.6.2. Acceptance

As detailed earlier in this chapter, stigma is a problem that has been faced by all but two of the respondents. Stigma is often the cause of non-disclosure as people fear the negative reactions of others. On the other hand, the support group accepts all its members and does not assign blame to people for being HIV-positive. How this support has been of value is shown by the following example.

S8 said that attending the support group had given her courage to admit to others that she was HIV-positive. She told of a community meeting which she had attended where she had stood up and had disclosed her status. Many others at the meeting had followed suit and she felt that a blow to stigma had been dealt at that meeting.

This, however, was not the view of the majority of respondents many of whom said they would be interviewed only on condition that they could not be identified. The researcher was also told she would not be allowed to take photographs. Although respondents felt safe within the confines of the support group, because stigma was not an issue there, they still believed that they would be stigmatised outside of the group if they admitted their membership of the support group.

When S15 first joined the HIV/AIDS support group she was given a T-shirt with an HIV logo. She remembers that it was a very hot day but she had a jacket with her which she quickly put on and zipped up right to the top so that nobody could see the T-shirt. She needed help which the support group could offer her and thus she felt obliged to wear the garment, but she did not want anyone else to see it or to know her HIV status.

One of the respondents was openly wearing a T-shirt with an HIV logo and the researcher enquired whether she did not mind wearing it. She said that she told people that she was wearing the garment in solidarity with all the HIV-positive people in Africa but she would not admit to them to being HIV-positive herself. The support that the group members receive within the group structure, therefore, is not perceived to spread to the broader community at present and stigma remains an ongoing problem. The focus group of facilitators confirmed that stigma in the community remained a major problem.

One of the older facilitators said that she remembered when cancer was stigmatised so, hopefully, HIV/AIDS would also similarly be de-stigmatised as time passed and people became better educated regarding HIV/AIDS.

### 5.6.3. Emotional support

All of the respondents said that they had benefited greatly by attending the HIV/AIDS support group in Khayelitsha as they had found a safe place where they could communicate with others without fear of rejection or discrimination. They felt they could openly speak to people in the group about their problems as they were all in the same situation. Respondents said that the ways in which they received support from the group was knowing that they were not alone in the world and knowing that their problems could be discussed and shared and advice could be sought, if necessary.

Everyone in the group was in a similar position and they could therefore understand what the other members were feeling and experiencing. Many of the respondents felt that the support of and acceptance by the other group members and the facilitators had given them the courage to face the world again. They had become more confident and were able to live life more optimistically. Because of this confidence, members felt more in control of their own lives.

S2 put it well. She told the researcher what she gained from attending the support group:

“When I am hungry, I can eat;  
When I have problems, I can get help;  
When I am lonely, I am not alone;  
When I am sad, I can laugh”.

Evidence shows that positive social and family relationships can “lessen the effects of stress on an individual and can reduce illness and death” (Carson, Butcher & Coleman, 1988). In this study, support group membership appears to have been instrumental in changing respondents’ reactions and emotions from those of passivity, helplessness, anxiety and depression to those of being more positive about the future and believing themselves to have a measure of control over their lives.

#### **5.6.4. Skills training and material resources**

The financial situation of all the women in the study sample, as shown earlier in this chapter, is tenuous and the women and their dependents have very meagre financial resources. Skills training and material aid is therefore of importance to them. The focus group of facilitators and the volunteer leader informed the researcher that a lack of financial resources is a problem for all of the support group members.

As mentioned earlier members are taught to work in the garden so that they can start their own vegetable patch at home, if they have the space.

S20's husband works in the garden and it was reported that this has given him a new lease on life.

S18 also works in the garden and she has now started her own small garden at home.

The volunteer leader and the focus group of facilitators said that income generation is encouraged and support group members are taught to do sewing and beadwork. This they can do at their homes and the finished products are then sold. They said they received overseas orders for their goods and popular items were beaded AIDS emblems and also the South African flag. Members are also allowed to sell their creations privately and thus earn extra income.

#### **5.6. CONCLUSION**

This chapter has described the findings of this research project. It has highlighted the finding that, before joining the support group, nineteen of the respondents experienced feelings of helplessness, anxiety and depression and believed there was nothing they could do to help themselves after being diagnosed as HIV-positive. However, after having joined the support group and being accepted there, receiving factual information regarding HIV/AIDS and being informed as to what they can do to lead more positive and healthy lives and also seeing people who are still alive after many years, they have realised that there is life after an HIV-positive diagnosis.

In addition to these advantages to those attending the support group, this chapter has also documented the on-going problems experienced by members particularly those related to stigma and poverty.

The following chapter will discuss the conclusions reached regarding these findings and offer recommendations.

University of Cape Town

## **CHAPTER 6 CONCLUSIONS AND RECOMMENDATIONS**

### **6.1. INTRODUCTION TO THE CHAPTER**

This chapter highlights the conclusions reached in view of the findings for each objective as outlined in Chapter 5. As a result of and in line with these conclusions, recommendations in terms of intervention and practice, policy and further research are also suggested.

### **6.2. OBJECTIVE 1: TO DETERMINE THE REACTIONS AND BEHAVIOUR OF WOMEN AFTER BEING DIAGNOSED AS HIV-POSITIVE**

From the data gathered, the researcher concludes that nineteen of the respondents exhibited symptoms associated with learned helplessness after being diagnosed as being HIV-positive. Although this study did not purport to establish if an HIV-positive diagnosis caused learned helplessness, the evidence from the data suggests that most of the respondents had learned, by various means, that they were helpless in relation to this disease. 19 of the 20 respondents reported that they were devastated after receiving their diagnosis and, as shown in chapter 5, significant emotional trauma, often for prolonged periods, was experienced as a result of this.

It needs, however, to be noted that there are also other important issues in the lives of these respondents which could have lead to feelings of helplessness, lack of motivation, anxiety and depression. For example, difficult living conditions and a lack of financial resources could also have played an important role in producing a sense of helplessness. However, it appears that it was the new knowledge that they were HIV-positive that evoked these reactions most strongly at the time of diagnosis.

In addition, the ability of the respondents to assimilate the information given them immediately after receiving an HIV-positive diagnosis appeared to have been reduced. They may have been in shock so were not able to fully comprehend what they were told. Although only a small sample of women were interviewed, it is suggested that many women and men who receive such life-changing news would react in a similar manner.

Therefore the following recommendations concerning intervention and practice are made regarding imparting this knowledge to newly diagnosed HIV-positive patients.

### **6.2.1. Recommendation: Communication of an HIV-positive diagnosis**

It is recommended that the communication of an HIV-positive diagnosis takes place in particular circumstances as described below.

Although it is recognised that there are financial constraints on health care systems, it is recommended that a follow-up counselling session be held a few days after the initial meeting, during which time newly HIV-positive diagnosed individuals can read some literature and there can then be an interactional discussion forum rather than an educational lecture. Illiterate persons can also benefit from a further meeting, where information previously given, can be discussed so as to assess the extent of assimilation of vital knowledge. This information should include facts concerning depression, anxiety and stress which are normal reactions to trauma, and people should be made aware of their possible negative reactions to an HIV-positive diagnosis and how this may be alleviated. It is important that these people receive accurate and timely information on HIV/AIDS so as to minimize their anguish. Furthermore, salient information could help them to take the necessary steps to remain well for as long as possible.

### **6.2.2. Recommendation: Referral to support groups**

It is recommended that individuals who are diagnosed HIV-positive immediately be referred to existing support groups where they can be helped to face their situation more positively and to take the necessary measures to optimize their well-being. Follow-up calls should be made to these people to encourage them to join a support group if they have not already done so, where they can share in the therapeutic gains of acceptance, empathy, support and education.

Further recommendations pertaining to support groups feature later in this chapter.

### **6.2.3. Recommendation: Empathy, acceptance and support**

It is recommended that the same qualities of empathy, acceptance and support should be evident when counselling takes place, so that newly diagnosed HIV-positive individuals do not feel stigmatised and discriminated against. Counsellors must be fully aware of people's fear of prejudices and no blame should be attached to people who are being tested or who are found to be HIV-positive. Since understaffing and overcrowding could lead to difficulties in providing quality time with each new HIV-diagnosed individual, it is important that optimum use be made of the time spent with each person.

### **6.2.4. Recommendation: Ongoing Counselling**

It is recommended that free ongoing counselling be made available for those individuals who continue to experience emotional distress and who cannot afford the fees of private counsellors.

These recommendations are made as, given the nature of HIV/AIDS, it is important that newly diagnosed HIV-positive individuals receive and assimilate timely factual knowledge regarding the disease. It is also important that information concerning this condition be imparted sensitively, taking the complexities of reactions to an HIV-positive diagnosis into account.

## **6.3: OBJECTIVE 2: TO DETERMINE THE EXTENT OF THE WOMEN'S KNOWLEDGE OF HIV/AIDS AND HOW THIS INFLUENCED THEIR REACTIONS AFTER BEING DIAGNOSED AS HIV-POSITIVE.**

The researcher concludes that most of the respondents had inculcated only the negative and fatalistic aspects of HIV/AIDS in their bank of knowledge regarding this disease. This has serious negative repercussions as it appears to have contributed to behaviour symptomatic of learned helplessness. Knowledge or lack thereof plays a vital role in the control and management of HIV/AIDS. In this regard, factual, realistic, relevant and appropriate knowledge is necessary in order to gain mastery. Myths, misinformation and opposing messages lead to confusion and obfuscation.

It would appear that much needed information is not being communicated appropriately or optimally or that it is not being internalised by the recipient. It seems that the respondents had not absorbed positive messages regarding HIV/AIDS. Rather, the negative, sensationalist broadcasting of fatalism and death voyeurism appear to have had a greater impact on the way HIV/AIDS was perceived by the respondents.

Coupled to this is the confusion spread by governmental agencies and high-ranking politicians concerning the treatment of AIDS and even the cause of AIDS, as described in Chapter 2. South Africa's ruling party has been elected by the majority of citizens who set store by what the politicians advise and trust that actions to maximise the welfare of the populace will prevail. At the Durban AIDS conference as referred to previously, the World Bank's Mamphela Ramphele "pointed to South African society and its low levels of literacy, numeracy and basic scientific understanding as particularly vulnerable to confusing advice" (Caelers, 2005). This is important as it would appear that the lack of factual and relevant knowledge, misinformation, confusing and conflicting information and advice, and myths contributed to feelings of helplessness and hopelessness experienced by 19 of the 20 respondents.

HIV/AIDS affects many people in South Africa, both directly and indirectly. Approximately six million HIV-positive individuals affect many millions more who are family members, friends, employers, medical staff and HIV/AIDS organisation members, amongst others. Education concerning HIV/AIDS therefore serves an important function.

Furthermore, as it is said that most South Africans have access to the media it, too, can have great potential for fostering more positive beliefs regarding this illness. Therefore the following recommendations are suggested.

### **6.3.1. Recommendation: The media**

It is recommended that the media be used to educate and inform its audience about HIV/AIDS rather than present HIV/AIDS stories that simply sensationalise the disease and its consequences. How the mass media portrays the disease of HIV/AIDS has significant consequences for its audiences.

It is realised that business concerns, including the media, need to make profits and newsworthy and sensationalist stories sell well and provide for these profits. However, as shown in Chapter 5, these can have a negative impact on people's perceptions of this disease and can lead to intense emotional distress.

Therefore, it is recommended that media reporting presents HIV/AIDS as a challenge rather than a threat, which may mobilize people to bring coping mechanisms into play, thereby leading to the optimisation of healthy and productive lives for HIV-positive individuals.

### **6.3.2. Recommendation: Government messages and action.**

Like the media, the government has a significant role to play in the communication of messages regarding HIV/AIDS. It is recommended that conflicting messages and advice from government officials be eliminated as people's perceptions are influenced by this.

This applies not only to what the government says, but also to what it does. It is recommended that antiretroviral treatment (ART) be readily available for all those in need of it. If people are educated regarding HIV/AIDS and its treatment, they should be able to access this medication when needed.

### **6.4. OBJECTIVE 3: TO DESCRIBE THE EFFECT OF STIGMA ON HIV-POSITIVE WOMEN**

The evidence from the data collected in this study suggests that the fear of stigmatisation plays an important role in the non-disclosure of a person's HIV-positive status. This can have negative consequences for the health of both the HIV-infected person as well as partners. The fear of stigma can also delay the process of seeking assistance and support. Furthermore, this fear could lead to feelings of hopelessness, helplessness, anxiety and depression. The following recommendations are therefore made.

#### **6.4.1. Recommendation: Support groups**

It is recommended that HIV-positive individuals immediately join support groups which are important resources offering their members a meeting place without fear of stigmatization. This can contribute to the alleviation of mental stress experienced by HIV-positive individuals.

However, the study also showed that although respondents felt accepted by support group members they still carried the fear of stigmatization outside of the group. As stated previously, the sample size in the study was small, but stigma appears to be a very real problem for HIV-infected people. Part of the answer to this problem lies in the need for people to be educated regarding HIV/AIDS. Regarding stigma, the following additional recommendations are therefore made.

#### **6.4.2. Recommendation: The media**

It is recommended that HIV/AIDS infected people be portrayed in the mass media as normal functioning human beings with a manageable chronic illness rather than as ill, disabled, dying victims or members of marginalised groups. An example is the weekly column in the *Sunday Times* entitled “Everyone knows someone” which aims at encouraging people to know their HIV status and to destigmatise the infection.

If HIV-positive people are presented as ordinary human beings who live productive, meaningful and contented lives, yet experiencing everyday problems like everyone else, they would be seen as one of ‘us’ and not one of the ‘other’.

#### **6.4.3. Recommendation: School education**

It is recommended that education regarding HIV/AIDS be given from primary school level. Such educational programmes should not only offer information regarding the disease but also address the issue of stigmatization inherent in such an illness. Children can learn from an early age to accept HIV-positive peers and any form of discrimination or stigmatization should be disallowed. It is recommended that these educational programmes be continued throughout the child’s school career.

#### **6.4.4. Recommendation: Businesses**

In addition, it is recommended that companies conduct regular educational programmes regarding HIV/AIDS. It is further recommended that businesses take steps to eliminate stigmatization inherent in company policy. Furthermore, steps should be taken to eliminate discrimination against and stigmatization of HIV-positive individuals in the workplace. Although only two of the women in this study were working, many other HIV-positive individuals are employed.

#### **6.4.5. Recommendation: Outreach programmes**

It is recommended that support groups establish outreach programmes regarding HIV/AIDS which include informative seminars held within communities enabling the dissemination of information and knowledge regarding this disease to local community members.

The recommendations as discussed above point to the significance of factual and relevant information regarding HIV/AIDS being learnt from an early age and continued throughout life. This could contribute towards the destigmatization related to this illness.

#### **6.5. OBJECTIVE 4: TO EXPLORE THE RESPONDENTS' FINANCIAL RESOURCES WHICH COULD EITHER FACILITATE OR MILITATE AGAINST THE LEADING OF AN OPTIMALLY HEALTHY LIFESTYLE**

The data collected in the study indicates that the financial position of all the women interviewed is tenuous and that although in the support group they are taught to eat healthily, they do not have the financial means to provide for this. Lack of resources and constant financial struggle, as described by many of the respondents, play a significant role in their feelings of depression and helplessness. Furthermore, the lack of resources militates against HIV-infected individuals living a lifestyle conducive to optimal health.

At present it seems possible that there are HIV-positive women who are producing children for their financial value of a monthly child support grant. If these mothers die within the next few years they will leave behind young orphans who need to be cared for by government and it is possible that some of these offspring themselves may present as HIV-positive, creating further long-term costs.

There are at present no government grants specifically for people infected with and suffering from HIV/AIDS. The following recommendations regarding policy are therefore suggested.

#### **6.5.1. Recommendation: Government grants and assistance**

It is recommended that an assistance grant be issued and that facilities be provided to aid HIV-positive individuals in their quest to optimise their chances for a healthy and longer lifespan. This may be an idealistic proposition but long-term benefits could prove cost-effective.

#### **6.5.2. Recommendation: Female condoms**

It is recommended that female condoms be freely distributed to sexually active women, which obviates the need for them to negotiate their partner's condom use. This may be an expensive exercise, but could prove cost-effective in the long term, by decreasing the number of future HIV-positive individuals.

#### **6.5.3. Recommendation: Skills training**

It is recommended that skills training programmes be implemented to provide teaching of marketable skills to unemployed HIV-positive individuals. Skills training, leading to a possible additional means of support, can produce a sense of achievement and can also enhance the confidence and self-esteem of those who can attain greater self-sufficiency by increasing their earning capacity.

These recommendations have been made as it is important to educate HIV-positive people regarding the means to ensure an optimally healthy lifestyle. However, if people have no resources to implement or follow these regimes, even greater despondency could ensue.

#### **6.6. OBJECTIVE 5: TO DISCOVER THE NATURE OF SUPPORT SYSTEMS WHICH ARE HELPFUL AND BENEFICIAL TO HIV-POSITIVE WOMEN**

From the evidence gained in this study the researcher concludes that support groups offer a much needed service to HIV-positive individuals in terms of education, acceptance, support and skills training. Furthermore, as there is a reported increase in HIV/AIDS incidence, the need for support groups for HIV-positive individuals is increasing. Education and knowledge plays an important role in these groups.

However, although education through factual knowledge appears to have been beneficial for all of the respondents in the study, many anomalies exist. Healthy eating is advocated, but a lack of financial resources militates against optimal attainment of this goal. Safe sex by means of condom use is propounded, but partners often refuse to comply or the women may not have disclosed their HIV-positive status and the need for condoms would then be questioned. The social position of the women interviewed often militates against making optimal use of information gained in the realm of prevention. Furthermore, as stated previously, child support grants make child bearing a viable proposition for some women. Despite these incongruities, it appears that education has made a positive contribution to the lives of these women.

However, in order to provide optimal benefits, education while retaining its factual content, needs to be adapted to the prevailing circumstances and situations of HIV-positively diagnosed women so that optimism instead of helplessness regarding their future prevails. The following recommendations are suggested in regard to education and information imparted and activities participated in at support groups.

### **6.6.1. Recommendation: Education and information**

It is recommended that information regarding HIV/AIDS is regularly updated and that members are kept informed of new developments as they occur. The facilitators of the group should receive ongoing training and experts in the field of HIV/AIDS should be enlisted to address the group on various aspects of the disease.

Everyone who attends these groups should be given all the information necessary to ensure that steps can be taken to maintain optimal health as far as is possible. Facilitators should be knowledgeable concerning opportunistic diseases that attack those with weakened immune systems and this knowledge should be shared with members, so that they can seek help if symptoms arise. Furthermore, members should be made aware of treatment availability and procedures and should be encouraged to comply with treatment regimes where this is indicated. In this regard, support group members should be encouraged to take note of their CD4 cell count so that ARV treatment may be sought when a CD4 cell count of 200 and below is reached.

### **6.6.2. Recommendation: Stress management programmes**

It is recommended that not only the physical condition but also the mental state of HIV-positive support group members be addressed. Information regarding stress, anxiety, depression and helplessness should be forthcoming. In conjunction with this, the means for the alleviation of these conditions and stress management programmes should form part of the support group routine. It is also recommended that exercise programmes be introduced and encouraged.

### **6.6.3. Recommendation: Assertiveness skills**

It is recommended that women in the support group should be taught assertiveness skills and the group should interactively discuss the role of women in society and their rights within relationships. Men also attend these groups and it is important that they, too, be involved in these discussions where the roles of men and women may be openly debated.

It is difficult to change informal social institutions and if these dictate the subservience of women, this cannot be altered easily but a beginning can be made where women are taught that they, too, have rights and needs which should be addressed.

#### **6.6.4. Recommendation: Networking opportunities**

It is recommended that the Khayelitsha HIV/AIDS support group involved in this study look at the possibility of twinning with a similar international group. Information can be exchanged regarding measures used to make life easier, healthier and less stressful for HIV-positive members. This would introduce a new dimension and novel perspective in the lives of the local support group members who could become acquainted with the ways in which others deal with a situation which they may see as chronic rather than terminal.

Such networking opportunities could expand the present boundaries of the support group by introducing new ideas and different perspectives not only regarding HIV/AIDS, but also concerning the quality of life which can be enjoyed whilst being HIV-positive.

#### **6.6.5. Recommendation: Income generation and skills training**

It is recommended that income generation be emphasised as the employment opportunities for women living in a township are very meagre. Opportunities for export of goods should be expanded if possible so as to provide additional support group members with an opportunity to obtain an income. If twinning with an overseas support group became a reality, their members could be encouraged to promote these local products for sale in their country.

Skills training and job provision could lead to far greater gains for all, not only financially, but also in terms of increased self-esteem and self-sufficiency. Increased self-reliance could lead to women developing a greater sense of independence and this could have a domino effect in the changing of informal institutions, e.g. subservience. If women became self-sufficient, they would not have to rely on partners to provide them with a livelihood and may, therefore, be able to have a greater say in matters of sex and condom use.

## **6.7. SUGGESTIONS FOR FURTHER RESEARCH**

This study has highlighted the need for the empowerment of socially and financially disadvantaged HIV-positive women. Future research could examine more extensively the roles which issues of stigma, informal as well as formal institutions and lack of financial resources play in creating barriers to the future well-being of these women. More importantly, research into the means by which these negative influences can be reversed is called for.

University of Cape Town

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## **APPENDIX 1**

### **Questions put to the Volunteer Leader and a focus group of facilitators of an HIV/AIDS Support Group in Khayelitsha.**

1. What are your perceptions regarding women's emotions and behaviour when they first join the support group?
2. What do you perceive their major problems to be?
2. Is stigma a problem?
3. How effective do you think their coping strategies have been before joining the support group?
4. What is the extent of their knowledge regarding HIV/AIDS when they first join the group?
5. What does the support group offer them?
6. Do you believe that the support group has positive and beneficial value for the members?
7. If yes, in what way is it beneficial?

## APPENDIX 2

### INTERVIEW SCHEDULE

1. What was your life like before you were diagnosed HIV-positive?
  - (a) Who were you living with?
  - (b) Were you working?
  - (c) How was your relationship with your family, partner and friends?
2. Before you were diagnosed, what did you know about HIV/AIDS?
3. Where did you gain this knowledge?
4. Did you know anybody who was HIV-positive or who had AIDS?
5. Who were they and what relationship did you have with them?
6. When did you first find out that you were HIV-positive?
7. How did this happen?
8. What was your reaction to this news?
9. What did you think would happen to you when told you were HIV-positive?
10. What information were you given after diagnosis?
11. What did you do after you were given the HIV-positive diagnosis?
12. Did your behaviour change in any way after the diagnosis?

13. What feelings and emotions did you experience?
14. Did you do anything to help yourself?
15. Did you tell anybody about your positive status?
16. What was their reaction?
17. Were you stigmatised?
18. In what way did this happen?
19. How did your life change after you were diagnosed HIV-positive?
20. What financial resources do you have?
21. When did you first join the HIV/AIDS support group?
22. Have you benefited from attending the support group?
23. In what way have you benefited?
24. What has the support group offered you which has been helpful?