

ISSUES OF DISCLOSURE IN  
RELATION TO HIV AND AIDS

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# ISSUES OF DISCLOSURE IN RELATION TO HIV AND AIDS

by

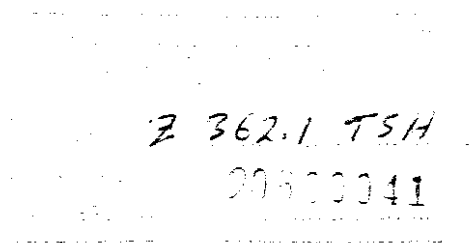
**Phumelele Ritta Tshabalala**

A Thesis submitted in fulfillment of the requirements for the degree of PhD  
Community Psychology in the Department of Psychology, University of  
Zululand.

**PROMOTER:** .....

**DR. R.M. MADHLOMO-SIBIYA**

**MAY, 2007**



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## **ANNEXURES**

**ANNEXURE A** - Proposed Intervention Programme

**ANNEXURE B** - The Questionnaire

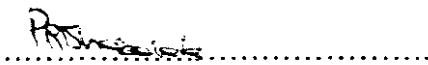
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## **DECLARATION**

I, Phumelele Ritta Tshahalala hereby declare that the work: Issues of Disclosure in Relation to HIV and AIDS is my original work. All sources consulted or cited have been acknowledged in the text as well as in the list of references.

A handwritten signature in black ink, appearing to read 'Phumelele Ritta Tshabalala', is positioned above a horizontal dotted line.

**Phumelele Ritta Tshabalala**

February, 2007

## **ACKNOWLEDGEMENTS**

I wish to express my sincere gratitude and appreciation to the following people for their resolute support, assistance and endless contribution to this study:

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- It is with some significance that I record my further appreciation to members of the support group who participated in this project

## **DEDICATION**

This work is dedicated to my husband, Nono, my late father and mother-in-law, my parents, my two daughters Nqobile and Nomfundo, and son Andile.

## **ABSTRACT**

The major aim of the study was to determine whether broad-based initiatives, such as community based stigma reduction intervention programmes (later) based on the findings of the study, could have an impact on the uptake of HIV-testing and disclosure rate. The total sample comprised of 15 females and 15 males that were chosen from one of the support groups based at one of the selected Hospitals in KwaZulu-Natal Province. With the assistance of the hospital officials, the researcher was able to use the purposive sampling technique in selecting the respondents. From the themes, it became evident that people living with HIV and AIDS are faced with an important dilemma regarding whether or not they should reveal the HIV-positive status to significant others. In-depth interviews with the focus groups produced the following themes as accounts of emotional observations: isolation, social stigma, anger, revenge and depression. In the light of the findings of the study, a need arose for the establishment of an intervention programme aimed at addressing the common barriers associated with HIV disclosure. Community Psychology in particular, played a major role in shaping this study because of its action focus on groups.



## **CHAPTER ONE**

### **INTRODUCTION TO THE STUDY**

#### **1.1 Introduction**

In mid -2006, the Joint United Nations Programme on HIV/AIDS (UNAIDS) published an estimated 5. 5 million people including 240 000 children younger than 15 years, were living with HIV in South Africa. In mid-2007, the South African Department of Health, in collaboration with UNAIDS, World Health Organization (WHO) and other groups, published an updated estimate of 18.34% prevalence in people aged 15-49 years old in 2006. This equates to around 5.41 million people living HIV in 2006, including 257,000 children. (UNAIDS, 2006).

The Actuarial Society of South African model (ASSA) of 2006, produced a similar estimate of 5.4 million people living with HIV in mid 2006, or around 11% of the total population in South Africa. It predicted that the number will exceed 6 million by 2015, by which time around 5.4 million South Africans will have died of AIDS. (Demographic Impact of HIV and AIDS, 2006).

In 2006, it was estimated that in Sub-Saharan Africa, 24.7 million people were infected with HIV. AIDS deaths in Sub-Saharan Africa, represents 72% of global AIDS deaths. Across Sub- Saharan Africa, women are more likely than men to be infected with HIV, and they are more likely to be the ones caring for people infected with HIV. (WHO/UNAIDS, 2006)

As a result of these high numbers, support issues for people living with HIV are of growing concern for Aids service organizations, health care providers, policy makers and more importantly for individuals themselves, their families and care-givers as it influences disclosure. This is because disclosure is often followed by major life-changing consequences (Leserman, 1997).

Disclosing an HIV-positive status to others is a primary and immediate concern to those infected. It is often an emotionally charged and complex action and the decision too is difficult for individuals to make. Van Wyk (1999) described two extreme responses. At one extreme, there is a desire to withdraw and isolate, refusing to tell anyone. This is because disclosure can expose HIV-positive individuals to stigmatisation, discrimination, isolation, and rejection by family, friends and community (Ewing, 2003). On the other extreme, there is the desire to “tell the world.” Neither of these extremes is adaptive. Nevertheless, disclosure is an issue that all individuals face, since it is a prerequisite for proper health care and receipt of appropriate emotional support from others (Derlega, Winstead & Folk-Barron, 2001). Support can therefore help the individual to accept his or her status, and the stress of coping on his or her own can be reduced.

Disclosure is an important public health goal for a number of different reasons. Firstly, disclosure may motivate sexual partners to seek testing, change behaviour and ultimately decrease the transmission of HIV (Ewing, 2003). Secondly,

disclosure has a number of potential benefits for the individual including increased opportunities for social support, improved access to necessary medical care including Antiretroviral treatment, increased opportunities to discuss and implement HIV risk reduction with partners, and increased opportunities to plan for the future (Kalichman, 1998). Finally, it can also promote responsibility and help to reduce the stigma, discrimination and denial that are associated with HIV and AIDS (Lovejoy, 1990).

Research conducted by Duffy (1994) suggested that disclosing an HIV-positive diagnosis to another individual may be an important contributor to one's perceived social support. The relationship between social support and disclosure may influence psychological adjustment (Moneyham & Seal, 1996). For example, HIV-positive individuals who share their status with a family member or their partners demonstrated significantly lower levels of emotional distress than those who chose to keep their status secret (Armistead & Tanenbaum, 2001).

On the other hand, some researchers have suggested that disclosure of HIV-positive status may provoke violence in intimate relationships (Glenen & Zierier, 1997). The kind of violence that may occur can be physical or emotional, combined with verbal abuse. People living with HIV may need a great deal of support in order to deal with the issue of violence around disclosure.

Culture can also provide a context within which disclosure occurs. People from different cultures may also differ in their views of disclosure. Societal norms, values and expectations about what is appropriate to reveal and not to reveal are socially learned and differ from culture to culture (Serovich, 2000).

## **1.2 Research questions**

- 1) Is it important to disclose one's HIV status?
- 2) What issues surround disclosure? What leads to disclosure or non-disclosure? How can the public create an environment that is conducive for disclosure?
- 3) How can HIV-positive individuals be empowered to disclose and then seek appropriate support and counselling?
- 4) What is the psychological impact of disclosing one's HIV status?

## **1.3 Motivation of the study**

As a PhD Community Psychology student, the researcher has had informal contact and conversations with HIV/AIDS-infected individuals in one of the local support groups. The issues and impact of disclosure around HIV/AIDS are a growing concern for them. It emerged during the discussions with HIV-infected individuals that because AIDS is still highly stigmatised, most of the individuals

Lack social support from friends, families and partners. Thus, because of the stigma, fear and anger, HIV-positive individuals often find themselves rejected by families and friends. As a result, the researcher saw the need to conduct an in-depth study around the issues of HIV/AIDS disclosure.

#### **1.4 Aim and objectives of the study**

The objectives of the study were:

- 1) To reveal to the public a conducive environment for disclosure.
- 2) To establish the importance of and to assess the psychological impact of disclosing one's HIV-positive status.
- 3) To empower HIV-positive individuals to seek appropriate support and counselling.

Ultimately, the aim of the study was to provide the researcher with an understanding of the issues of disclosure that would form a basis for the development of a programme related to HIV/AIDS disclosure.

## **1.5 Definition of concepts**

### **1.5.1 Disclosure**

Disclosure, in the context of this research, means informing a person organization, media about one's HIV status. It could be one's friend, family member, partner or colleague (Omarzu, 2000).

### **1.5.2 Stigma**

HIV-related stigma refers to all unfavourable attitudes, beliefs and policies directed toward people perceived to have HIV/AIDS as well as toward their significant others and loved ones, close associates, social groups and communities (Moneyham & Seal, 1996).

Gilmore (1994) defined stigma as an undesirable or discrediting attribute that an individual possesses, thus reducing that individual's status in the eyes of society.

### **1.5.3 Discrimination**

Discrimination refers to negative behaviours or actions that are directed towards members of social groups who are objects of prejudice (Baron & Byne, 1994). Therefore discrimination is prejudice in action.

### **1.5.4 “AIDS”**

“AIDS” means Acquired Immune Deficiency Syndrome (Weiner, 1998).

### **1.5.5 “HIV”**

“HIV” means Human Immunodeficiency Virus (Weiner, 1998).

### **1.5.6 HIV status**

HIV status in this study refers to HIV positive status.

## **1.6 Scope and delimitation of the study**

The study focused on the population of HIV-positive patients from a local support

group.

## **1.7 The significance of the study**

- \* This study has contributed scientific information and conclusions concerning the issues of disclosure.
- \* In addition, this study has led to the establishment of an intervention Programme to assist HIV-infected clients to disclose their status in a more comfortable manner.
- \* It addressed attitudes, myths and misconception around HIV/AIDS.
- \* It has also contributed towards positive living to those who disclose their HIV status.

## **1.8 Résumé**

Disclosing an HIV-positive status to others is a primary and immediate concern to those infected. Disclosure is an issue that all clients face, since it is a prerequisite for proper health care and receipt of emotional support from others. Societal norms, values, and expectations about what is appropriate to reveal or not to reveal are socially learned and differ from culture to culture. Literature will be reviewed and presented in the next chapter.



## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.1 Introduction**

Theories about the origins of HIV/AIDS are numerous and varied. Some of the most common theories are the following, 'The Hunter' theory, the Oral Polio Vaccine (OPV) theory, the Contaminated Needle theory, the Colonialism theory and the Conspiracy theory.

This chapter will also include the discussion on HIV disclosure, the psychological impact of HIV on the individual, families, children, education, economy, health services, friends and partners. The myths and barriers about HIV/AIDS, as well as the projections and demographic impact of the epidemic in South Africa will be discussed.

#### **2.2 Theoretical approaches to HIV/AIDS**

The following theories reflect the perceptions of people, in general about HIV/AIDS and therefore affect prevention and disclosure.

##### **2.2.1 The Hunter theory**

The most commonly accepted theory is 'The Hunter' theory. In this scenario, the Simian (monkey) Immunodeficiency Virus (SIV) was

transferred to humans as a result of chimpanzees being killed and eaten or their blood getting into cuts or wounds of the hunter. Normally, the hunter's body would have fought off SIV, but on a few occasions, it adapted itself within its new human host and became HIV-1.

In an article published in *The Lancet* (2004), it also shows how retroviral transfer from primates to hunters is still occurring even today. For example, in a sample of 1099 individuals from Cameroon, it was discovered that up to ten were infected with SFV (Simian Foamy Virus) (1%), an illness like SIV, which was previously thought only to infect primates. All these infections were believed to have been acquired through the butchering and consumption of monkey and ape meat. Discoveries such as these have led to calls for an outright ban on bush-meat hunting to prevent Simian viruses being passed to humans (Wolfe, Switzer, William, and Jean, 2004).

### **2.2.2 The Contaminated Needle theory**

This is an extension of the original 'hunter' theory. In the 1950's, the use of disposable plastic syringes became commonplace around the world as a cheap, sterile way to administer medicines. However, to African health-care professionals, working on inoculation and other medical programmes, the huge quantities of syringes needed would have been very costly. It is likely therefore that one single syringe

would have been used to inject a number of patients without any sterilization being carried out.

This would have rapidly transferred any viral particles (within the hunter's blood, for example) from one person to another, creating a huge potential for the virus to replicate in each new individual it entered, even though the Simian Immunodeficiency Virus (SIV) within the original person infected had not yet converted to HIV (<http://www.avert.org/origins.htm>).

### **2.2.3 The Oral Polio Vaccine (OPV) theory**

Some other controversial theories have contended that HIV was transferred via medical experiments. Blancou (2001) in his book, *The River*, suggested that HIV could be traced to the testing of an oral polio vaccine called Chat that was given to about a million people in the Belgian Congo, Ruanda and Burundi in the late 1950's. Hooper's belief is that Chat was grown in kidney cells taken from local chimps infected with SIV. Hooper then claims that this would have resulted in the contamination of the vaccine with chimp SIV, and a large number of people eventually became infected with HIV-1 (Blancou, 2001).

#### **2.2.4 The Colonialism theory**

The Colonialism theory or 'Heart of Darkness theory,' is based on the basic 'hunter' theory premise, but it more thoroughly explains how this original infection could have led to an epidemic.

During the late 19<sup>th</sup> and early 20<sup>th</sup> century, much of Africa was ruled by colonial forces. In areas such as Belgian Congo, and French Equatorial Africa, the colonial rule was very harsh and many Africans were forced into labour camps where sanitation was poor, food was scarce and physical demands were extreme. All these factors would have been sufficient to create poor health in anyone. So, Simian Immunodeficiency (SIV) could easily have infiltrated the labour force and taken advantage of their weakened immune systems to become HIV. A stray and perhaps sick chimpanzee with SIV would have made a welcome extra source of food for the labour force (<http://www.avert.org/origins.htm>).

Moore (2000) who first proposed the colonialism theory, believed that many of the labourers would have been inoculated with un-sterile needles against diseases such as Smallpox, and that many of the camps employed prostitutes to keep workers happy.

Such a situation created numerous possibilities for the transmission. A large number of labourers would have died before they even developed

the first symptoms of AIDS and those that did get sick would not have stood out as any different in an already disease-ridden population.

One final factor Moore (2000) uses to support his theory is the fact that the labour camps were set up during the time that HIV was first believed to have passed into humans during the late 19<sup>th</sup> and early 20<sup>th</sup> Century (<http://www.avert.org/origins.htm>).

### **2.2.5 The Conspiracy theory**

Some say that HIV is ‘man-made,’ while others say that HIV is a ‘conspiracy theory.’ A survey conducted in the United States, for example, identified a significant number of African Americans who believe that HIV was manufactured as part of the biological warfare programme aimed at wiping out a large number of blacks and homosexual people (<http://www.avert.org/origins.htm>).

A number of people were of the view that this was done under the auspices of the United States Federal ‘Special Cancer Virus Programme’ (SCVP), possibly with the help of the CIA. Others, on the other hand believe that the virus was spread either deliberately to thousands of people all over the world through the Smallpox Inoculation Programme, or to gay men through Hepatitis B vaccine trials (<http://www.avert.org/origins.htm>).

While none of these theories can be definitely disproved, the evidence they are based on (that the virus has been identified in people as far back as 1959) often ignores the clear link between SIV and HIV.

Finally, these theories fail to take into consideration the lack of genetic-engineering technology available to 'create' the virus at the time that AIDS first made its appearance (<http://www.avert.org/origins.htm>).

### **2.3 Disclosing of HIV status: patterns, reasons and reactions**

Disclosing one's HIV status is an emotionally difficult task for any individual. It raises issues of privacy, vulnerability, identification with a stigmatised role, and feelings of imposition on others (Liebert, 2001).

Individuals who are aware of their HIV sero-status are frequently confronted with the important, although difficult, decision of whether or not to disclose one's sero-status to others. The way each person experiences and copes with the illness is reflected in this choice (Levy, 1999).

Disclosure of HIV infection can lead to important social support that can mitigate the negative effects of stress (Hays, Mukusick, Pollack, Hillard, Hoff and Coates, 1993). Conversely, hiding one's status may not only preclude HIV-related social support and its attendant benefits but may also have direct

negative effects on disease progression for HIV positive individuals (Cole, 1996).

Social support theories distinguish between three basic types of support that appear most important for people with chronic illnesses namely, informational, emotional and tangible.

- Informal support: may accelerate recovery from illness and enhance treatment. Informal support has also been associated with positive outcomes, such as adjustment and coping with the illness.

Informal support makes patients feel accepted regardless of their conditions. It also acts as a buffer against the intense, negative emotional effects of the disease, and provide enduring interpersonal relations that can be relied on to provide emotional assistance. Thus, supporting others, may impact on how individuals view their illness and themselves.

- Emotional support: when faced with a life-threatening illness, individuals strive to find meaning in their lives, gaining a sense of control and restore self-esteem. Significant others may play a key role in these processes by offering emotional support, validating one's experiences and providing practical help and advice. Both informal and emotional support has been shown to reduce the distress of having a chronic illness, including HIV/AIDS (Simone, 2000).

- Tangible support: helping patients face the fears directly creates an intimacy that builds what Spiegel calls ‘social glue.’ Depending on the stage of their illness, people with HIV/AIDS may require help with activities of daily living such as grocery shopping, housekeeping and transportation. Women may need more assistance than men because they tend to have relatively higher levels of functional impairment and barriers to health care (e.g. transportation, unstable housing, competing time demands due to care giving responsibilities (<http://www.apa.org/pi/aids/major.html>)).

The following are some cases of HIV infected South Africans from Lusikisiki, a rural region in the Eastern Cape Province telling their stories including how they received social support from their families:

#### HIGHLIGHT

“My name is **Nomfumaneko**. I am fifteen years old. I started to be sick in May last year (2004).”

#### **NOMFUMANEKO CONTINUES....**

It was said I must have an HIV test. It was positive. My heart was very painful at the news, but I did not cry. The nurses told me I must not be scared and that if I take my medication, I am going to get better.

For a while I felt stronger, but now I cannot do anything. I am very weak. It is difficult for me to walk even a few steps. My sister helps me to wash. My family is supporting me. They come to sit with me



every time I take my medication. I feel very happy because they show me that they really love me.

I want to go back to school when I am better, so I can learn to be a nurse. My dream is to help other people who are very sick in the same way.

“Last November (2004) Nomfumaneko died.” Her Aunt Ntobile.

Source: Living with AIDS, by Gideon, 2005.

Another individual from Lusikisiki had this to say after discovering that she was HIV positive:

### HIGHLIGHT

My name is **NOZAMILE**. I am 22 years old, and I have four children. Last year I decided to get an HIV test because I had back pains, headaches, and diarrhoea. When they told me I was HIV-positive, I was very sad. If I die, I thought, who is going to care for my children?

I phoned my husband, who works at a gold mine, to tell him this news. He then told me he was HIV-positive as well and was already getting ARV treatment from the mine hospital. I was very angry and asked him why he came home with such a big disease when I had small children to bring up. He said he had been afraid to tell me that he had this disease.

I decided that I wanted to have all my children tested for HIV. The AIDS counsellor took a drop of blood from their fingers and put it on a small cardboard strip. Then we had to wait 15 minutes to see how many lines appeared. Two lines mean HIV-positive, but all my children had only one line. They will be able to lead healthy lives.

I have started to attend the support group at Xurana Clinic, and I like going there. Every time we open with a prayer and sing many songs. I was also part of a big church service in my village, where I was called forward for a special blessing. I was happy to receive such a blessing in front of so many people.

I have been taking ARV pills for two months now, and I am free in my heart. I can take care of my children, clean my house, look after the goats, fetch water and cook the food. I have decided to tell everybody that I have HIV. I want to live a better life, so I don't want to be hiding something like this.

SOURCE: Living with AIDS, by Gideon, 2005.

In the Everyone Knows Someone Campaign, by the Sunday Times News Paper, which is aimed at encouraging people to know their HIV status, the following is what Mangosuthu Buthelezi; President of Inkatha Freedom Party had to say about losing two of his children:

## HIGHLIGHT

### **I'll never forget my children's courage!**

Mangosuthu Buthelezi, President of the Inkatha Freedom Party, lost two of his children – Nelisuzulu and Mandisi Buthelezi to AIDS. As part of the Everyone Knows Someone campaign, he shares his story.

“It is, of course every parent's worst fear to outlive their children. It is a violation of the natural rhythm of life. The deaths of our two children, Nelisuzulu and Mandisa, from HIV/AIDS within a few months of each other in 2004 left Irene, my children and me, numb with grief. Yet, we knew that this was not a singular time of bereavement. We were going through what millions of South Africans are experiencing.

My decision to speak out about the cause of our children's death was difficult and personal. I felt I had a responsibility as a leader of my people to speak out against the stigma and silence, which are the main causes of the prolific spread of this deadly disease. I knew that I was taking a risk due to the sensitivities of such matters in the African culture. But I have never regretted it once. I hope my decision has made a small difference.

I did things that I would not normally countenance. For instance, I allowed myself to be filmed walking near my children's graves, for a British television station. I simply thought if the image helped, I

should do so.

Throughout my long exposure to HIV/AIDS through my personal and professional interests, my constituency and my closest family, I have never had the slightest doubt, that, together, we can stop the disease.

I have heard, and indeed experienced, many heartbreaking accounts of the devastation that this preventable plague has brought on communities. But I have also heard many stories of people and entire countries that, with qualified medical help, have successfully addressed the disease.

The HIV/AIDS pandemic is the most serious social-economic crisis South Africans have ever faced, apartheid included. It can only be tackled with genuine commitment and political will. From the highest to the lowest levels of government and civil society, the pandemic can only be defeated against a backdrop of hope.

A successful long-term strategy to defeat it can only work as a partnership between the infected/affected on the one hand, and private/public sectors and international organisations on the other. Unnecessary confusion regarding the cause and true danger of the disease must be rooted out once and for all.

Another key is to empower the vulnerable. In addition to HIV-positive pregnant women, a comprehensive roll-out programme must be extended to cover suckling babies, rape victims, prisoners and everyone diagnosed with HIV.

I personally, will never cease to campaign against the myth of “virgin cure,” for education and empowerment of women, for improvement of court procedures for rape victims, and for assistance to orphans and child-headed households.

As for Irene and me, life goes on, somehow. The relentless clock will not stop for anyone. Irene and I look after Mandisi’s son, and he brings much joy to our lives.

As for my dear children, I will never forget their doughty fight and their stubborn determination to live and, yes, smile in the most difficult of times. The human spirit is really quite glorious – even in the shadow of death.”

SOURCE: Sunday Times News Paper, 28<sup>th</sup> May, 2006.

In the same (Everyone Knows Someone) campaign by the Sunday Times News Paper, former President of South Africa, Nelson Mandela, had the following to say about the death of his son in 2002:

## HIGHLIGHT

### **I watched my son die'**

My son died of AIDS in 2002, aged 28. I am telling our story to underline the wide variations in HIV/AIDS' causes and effects – and current advances against it.

Andrew was gay and in 1982, we had discussed a terrifying illness reportedly emerging among young homosexual men in London where he lived. He had promised to take preventative measures with any partner.

In 1995 he learnt by chance, after a minor operation, that he was infected. The pathologist asked if he was homosexual, then said “Your blood test shows the HIV virus, which means you’ll get cancer and Aids and you’ll die. You people are society’s scrounge.”

There was no advise or counselling – just cruelty and misinformation. Andrew was only 21. The worse was to come. The partner he trusted admitted to purposely infecting him because his own family had rejected him, and he resented Andrew’s ease with being gay and my acceptance. Andrew reeled, but mustered his courage and vowed “to live until I die without harming anyone.”

In the ‘80s in England he remained silent about his status to avoid

losing his job and becoming a social pariah. His brother stood by him. Without any drugs generally available to combat the virus, Andrew relied on a healthy diet and gym. Above all, he lived with joyous zest for seven years. He told me: "I've lived 60 years in 28 – don't mourn that Ma."

The axe fell with shingles then a plunging CD4 cell count and eventually his entire nervous system failed. He died within seven months. I sat at his bedside, inspired and humbled by his indomitable spirit and wry humour.

Back in South Africa, I in turn remained silent. Denial or disgust was still 2002 society's response to AIDS and I didn't have the strength to fight back yet. I said he'd died of Leukaemia.

Our suffering was intensified by ignorance and enforced silence. Please don't replicate that unnecessarily. There are now enough enlightened people to defeat AIDS – but individually facing its facts honestly, responsibly and openly are the first essentials for that.

Dana Wakefield, Johannesburg

Source: (Sunday Times Newspaper, 7<sup>th</sup> May, 2006).

Further on, former President Nelson Mandela says that "we are all affected or infected by this disease and it is therefore very important to know your status. Silence is as big a killer as HIV/AIDS itself, and we

believe the Sunday Times campaign will help to fight against the stigma and discrimination associated with the disease. We wish the campaign well!”

The choice of disclosure is a complex decision. Though there is no clear indication, some general trends are seen in literature: for example, in the Western World, studies reveal that in most cases, friends are the first ones to be informed of one's serostatus. Sharing this with family member, if at all, is only done later (Hays et al., 1993; Simon et al., 1995; Stempel et al., 1995; Wolitsky et al., 1998).

Disclosure to a spouse or sex partner(s) is very important, particularly for preventing HIV transmission. Marks (1992, 1994) is of the opinion that disclosure to sexual partners needs to be facilitated, as many hesitate to do so due to fear of being rejected.

Judge Edwin Cameron who publicly declared his HIV-status had this to say: “I love being judge. The intellectual challenges are exhilarating... but, I am not only a judge. I am also living with AIDS. I am still the public office bearer in South Africa to have chosen to make public my HIV-status. I felt I was called to witness. I felt called to account for my survival in a country in which hundreds of thousands were dying. I did not feel I should remain silent” (Cameron, 2005).



Mansergh (1999) in his study found that 10% of HIV-positive individuals reported that their lovers left them upon hearing about their HIV status. Some of his respondents even reported physical abuse by their partners, anger and tension as well as loss of economic security.

Disclosure to health care providers has also become important. However, concerns such as fear of loss of confidentiality and difficulty associated with obtaining health insurance may lead to a delay in seeking health care among HIV-infected individuals (Wolitsky, 1998).

The influence of cultural values also plays an important part on the decision to disclose one's HIV-status to others. Studies among Latino men and women have revealed that cultural orientation and acculturation levels may influence the disclosure process (Manson, 1995).

In Africa, women are not necessarily in a position to make purely individual decisions about safe sex, since these decisions are intimately linked to social constructions of sexuality and the power relations that operate in cultures. Currently, Botswana has one of the highest recorded incidences of HIV infection in Africa. The rapid transmission of HIV in Botswana has been due to three main factors: the position of women in society, particularly their lack of power in negotiating sexual relationships, cultural attitudes to fertility, and social migration patterns (Strebel, 1993).

For many Africans, disclosure is usually restricted to family members or partners. Most chose a significant other, usually a close family member of the same generation.

Various studies in Africa have found that most married people do not inform their partner after positive diagnosis. This obviously has serious implications for couples where only one partner is HIV-positive. Studies also indicate that most African women believe they have a right to know the HIV-status of their partner.

In Asia, avoidance of conflict is paramount in people's decisions around disclosure. Most studies indicate that most HIV-positive Asians are strongly driven by wanting to protect their families from shame. The shame of being identified as a homosexual, drug user, and a sex worker results in most Asians keeping their diagnosis to themselves.

In the West, women are more likely to disclose to family members. For men, friends are more likely to be informed than family. American studies indicate that the majority of people inform their partner first, then friends, before they disclose to the wider family. One study found that disclosure is more common if a person is sick and they have large social networks to draw on (Blancou, 2001).

## **2.4 Impact of HIV**

An increased prevalence of HIV infection has contributed to a vicious cycle of illness, death, poverty and hardship. The severity and size of the epidemic make the fight against HIV and AIDS an unparalleled challenge (Bor, 1997).

### **2.4.1 The psychological impact of HIV on the individual**

The psychological impact or internal challenges a person with HIV/AIDS faces vary from individual to individual. Each HIV/AIDS situation is as unique as the people involved. There are individuals who might face catastrophic changes not only in their personal relationships, but in their physical bodies and their self-images and self-esteem (Watstein & Changler, 1998).

Individuals with HIV/AIDS may become withdrawn, aggressive, and rude to colleagues, friends and families. This may be because the infected person may feel victimized. Infected, and in some cases, affected people can experience a decrease in self-esteem as they are no longer confident in themselves or what they can achieve. This is likely caused by the stigma within society, against infected and affected people. According to Watstein and Changler (1998), coping with being infected involves confronting fear and denial while maintaining hope.

Persons with HIV/AIDS may be caused to see themselves as undesirable by others. This, in itself, is an emotional situation that can

cause infected people to withdraw, not disclose their feelings, and become socially isolated.

Eventually, this may lead to an emotional breakdown because these feelings continue to be suppressed. This isolation can have many consequences, including the loss of support by friends, families and partners.

#### **2.4.2 Psychological impact on families**

The stress of having a member of one's family HIV-positive is considerable (Wight, 2000). This stress arises from a number of different sources, some of which are discussed below. Preoccupation about the death of a loved one is painful in any circumstances. When this person is in the prime of his or her life, the tragedy tends to be greater than if a person has lived a long and fulfilled life.

The community ostracism because of the AIDS stigma puts added stress on those close to the infected person. In addition, the family members may suffer psychological distress if they themselves hold stigmatising attitudes towards people with HIV/AIDS. This could result in cognitive and emotional dissonance, with feelings of anger and resentment mixed with love and compassion. Such dissonance may or may not become resolved with time.

As the HIV-positive person becomes more ill, family responsibilities are forced to shift.

In many countries, women are the carers, producers and guardians of family life. This means that they bear the largest AIDS burden. As women often shoulder the burden of care when their adult children fall ill, they may later become surrogate parents to their bereaved grandchildren as was seen in the highlight of Dr M G Buthelezi. In some instances, families may have to withdraw young girls from school to care for ill family members with HIV.

The physical care of a person often becomes extremely stressful psychologically. Having to bath, feed and medically treat a deteriorating person is emotionally exhausting, especially if there is no relief. If there is more than one family member who is ill, which is not unusual with HIV pandemic, the resultant psychological impact is seriously made worse.

When the male head of a household becomes ill, women invariably take on the additional care duties. Providing care to an Aids patient is time-consuming, even more so when it is done on top of other household duties. A caregiver's burden is especially heavy when water must be fetched from a distance, and sanitation and washing chores cannot be carried out in or near the home. South Africa aptly illustrates this. It is one of the most developed countries on the continent yet, a

2002 survey of Aids-affected households found fewer than half had running water in the dwelling and almost a quarter of rural households had no toilet (Steinberg, Johnson, Schierhout, and Ndwega, 2002).

Young women widowed by AIDS may lose their land and property after their husbands die. Widows are often responsible for producing food for their families and may be unable to manage alone. As a result, some are driven to transactional sex in exchange for food and other commodities.

Another family constellation affected by HIV is one in which both parents of children are HIV+ (positive). These parents, in addition to dealing with challenges associated with their own serostatus, may face many other issues. For example, a study conducted by Goldie (1997) at a hospital for sick children in Toronto, described many of those challenges. In-depth interviews conducted with caregivers of children in families living with HIV from 1994 to 1996 in eight provinces; revealed the following five concerns: the future needs of children (e.g. choosing guardians), living with uncertainty and coping with stress, dealing with complex health and family relationship issues, dilemmas of disclosure and fear of discrimination, and the social and community experiences (e.g. effects of poverty).

Parents of HIV-positive adults may confront issues such as whether to disclose to their friends and relatives, weighing the desire for support

with the fear of discrimination and rejection. They may also struggle with coming to terms simultaneously with their children's HIV status. Another issue that may arise is if their HIV-positive adult child becomes incompetent to manage his or her affairs, parents may find themselves in roles of caregivers and or decision-makers in the legal or medical realm.

According to Walker (1991), how a family copes with any illness, including HIV depends on both the nature of the family organization and the belief system that govern the family's response to illness. The impact on the family also varies with their ethnicity, religion, race and social class and the family's relationship with the treatment providers (Rait, Ross & Rao, 1997).

#### **2.4.3 Psychological impact on affected and infected children**

The psychological impact on children who have an HIV-positive parent(s) also requires special attention in this study.

According to Mallmann (2002), there are a number of psychological factors affecting children of HIV/AIDS parents. A parent who is HIV infected may show less interest in the child due to the dramatic mood swings associated with the pressure of being infected. The child usually does not know what the problem is, that it is not his or her fault, and does not understand why the parent seems moody. The child

is likely to react with fear and anxiety and sometimes will blame him/herself. The child's world goes through many changes as the family structure and the way of doing things also changes, especially as the sick parent is unable to perform the normal household routines. The older children are expected to take up the responsibilities which are much beyond their capabilities. This is especially true in rural areas where the family responsibilities and needs are greater.

The psychosocial impact of stress, grief, avoidance and teasing by other children, social isolation and discrimination can lead to behavioural disturbances, self stigmatisation, and increased opportunities for abuse. Children may also suffer economic problems as the household provider becomes sick, cannot work, and lose their jobs (Tjikuna, 2002).

Collins-Jones in (Wild, 2001) found that, as a group, children who had multiple family members diagnosed with HIV/AIDS had clinically elevated levels of psychological distress. Nick and Villeges in (Wild, 2001) found that children of HIV-infected women suffered from heightened feelings of anxiety and depression, had difficulties with eating and somatisation problems such as migraines, stomach-aches and headaches. Forehand in (Wild, 2001), in a study of children of HIV-positive mothers, found that an 'experimental group' had poorer psychological adjustment than the control group.



Omarzu, (2000) found substantial Depression and Anxiety amongst a cohort of adolescents with HIV-positive parents. He found that young people who knew of their parent's HIV status showed more behavioural problems than those who did not. Significantly though, children bereaved by sudden, unexpected parental death have been shown to have more negative outcomes than children who have been prepared. Female adolescents displayed a significantly higher level of anxiety than their male counterparts. The research also showed that a 15-month coping skills intervention with HIV-positive parents and their adolescent children significantly reduced mental health problems amongst the adolescents.

Some researchers have observed symptoms associated with trauma, depression and lack of bonding and attachment in very young children. As a result, this may lead to children feeling deprived of their childhood, causing misery and sometimes ideation of suicide (Harhambo, 2004).

Children are also infected with the virus as a result of prenatal transmission or through sexual abuse. These children experience a complete loss of childhood since they are continuously sick. For an infected child, the fear of dying is constantly predominant. This, of course, impairs normal emotional and psychological functioning (Landman, 2001).

#### **2.4.4 Impact on education**

As HIV/AIDS spreads and starts affecting adolescents and the younger age groups, fewer children will be admitted into schools. Thus, teachers are likely to have to cope with poor performance on the part of pupils who are either infected with or affected by the disease. Absenteeism among teachers and pupils alike will increase, and sick leave requests will become more frequent. As the suffering and deaths brought about by the disease start making their impact in classrooms and lecture theatres, morale will drop and schools together with other academic institutions will be confronted with the need to provide emotional and psychological support to both educators and learners (Bezuidenhout, 2004).

#### **2.4.5 Impact on the economy**

An increase in death and illness in a population will inevitably have economic and social consequences. South Africa at the moment is experiencing an HIV epidemic. The AIDS epidemic is still developing.

While HIV epidemic is projected to peak around 2010, AIDS cases will continue to grow for more years to come. Ultimately, the economic impact will depend on how many people are infected and who they are. Economics does not value all lives equally. However, all people are consumers even if they are not producers.

Presently, South Africa is already battling with a shortage of skills. Aids will exacerbate this and raise remuneration and replacement costs for companies. There will be a smaller labour force with lower productivity and income at the same time as the demand grows for services such as health and welfare (Bezuidenhuot, 2004).

#### **2.4.6 Impact on health services**

Presently, it is estimated that 50% to 60% of admissions into public hospitals and medical wards are HIV/AIDS related. Thus, a Government's expenditure on health services is more likely to grow, and may be expected to account for the lion's share of the country's annual expenditure ([Http://www.apa.org/pi/aids/major.html](http://www.apa.org/pi/aids/major.html)).

The under-resourced health services are not able to cope with the increased burden of care. Some patients are being discharged to their homes, and there has been an increase in home-based care of AIDS victims (Bezuidenhout, 2004).

## **2.5 The most common barriers to disclosure**

### **2.5.1 Fear of rejection/discrimination**

HIV-infected people have many fears. Several studies have found that fear of social isolation and discrimination is an important barrier to disclosure of HIV status. Fear of discrimination can be further defined as fear of social discrimination leading to social isolation and lack of support and fear of socio-economic discrimination which many lead to problems with housing, jobs, income, insurance and other practical socio-economic considerations (Derlega, 2001).

In a study conducted by Moneyham and Seal (1996), it was found that concerns of discrimination were a major barrier to disclosure particularly in situations where disclosure involved people that participants felt had power over some aspect of their lives such as work or needed resources.

South Africa as with most other countries world wide, has reported a large number of incidents of rejection and discrimination. These include the murder of Mpo Mtloung together with her mother by Mpo's husband, who then also committed suicide (Treatment Action Campaign, 2000), not allowing HIV-positive children into schools (SAPA, 2002; Streak, 2001a), exclusions or attempted exclusions from

the workplace (Ngqalaza, 2000b), and in home communities (Gosling, 2000; Smetheram, 2001) and rejection from families.

### **2.5.2 Fear of abandonment**

In studies conducted in developing countries, the majority of women reported fear of abandonment and loss of economic support as the major barriers to disclosing an HIV status to a sexual partner. Abandonment by colleagues, friends and loved ones can cause one to lose confidence and a sense of one's social identity. The inability to continue to participate in social, sexual and loving relationships also diminishes an HIV infected individual's self-esteem (Gosling, 2000).

### **2.5.3 Aids-related stigma**

Aids-related stigma and discrimination directly hamper the effectiveness of AIDS responses. Stigma and concerns about discrimination constitute a major barrier to people coming forward to have an HIV test, and directly affect the likelihood of protective behaviours.

The following are some of the factors which contribute to HIV/AIDS-related stigma:

- HIV-AIDS is a life-threatening disease
- People are scared of contracting HIV

- The disease is associated with behaviours (such as sex between men and injecting drug-use) that are already stigmatised in many societies
- People living with HIV/AIDS are often thought of as being responsible for becoming infected
- Religious or moral belief lead some people to believe that having HIV/AIDS is the result of moral fault (such as promiscuity or 'deviant sex') that deserves to be punished (UNAIDS, 2004).

Research has revealed various forms and expressions of stigma as indicated hereunder:

- **Physical stigma**

The forms of physical stigma can be grouped into isolation and violence with the former being widespread and the latter less common. Physical isolation of people living with HIV and AIDS occurs in all locations, from the home to community gathering or public places like teashops, buses, trains, sports grounds, places of worship and also at work places, schools and hospitals. Within the home environment, common expressions marking and separating out typically shared objects like, clothes, eating utensils, bed linens and making those with HIV/AIDS sleep in separate rooms or eat alone .

One woman from Zambia had the following to say, “No one in Zambia would sit next to an HIV-positive individual on the bus... maybe you cough and everybody has their eyes on you.” Women’s lack of access to resources and dependence on husbands and families leaves them particularly vulnerable to abandonment, divorce and separation from children and with little resources to challenge these actions (USAID, 2000).

- **Verbal stigma**

A second form of stigma is verbal. This could involve direct (insulting, pointing fingers, taunting, or blaming) or more in indirect like gossip and rumours. Gossip and rumours focus on speculation about whether a person has HIV, usually because of visible signs, illness, behaviour or association with groups seen as “high risk.” Once a person is assumed to be HIV-positive, people often speculate about how he or she contracted HIV. This argument is well supported by the labelling approach which argues that having been stigmatised as HIV-positive, many people are driven to fulfil our expectations of them, because they have been labelled as HIV-positive, they come to see themselves as bad, and so, they continue not to look after themselves (Stark, 1994).

- **Social stigma**

A third form of stigma is social. Social stigma can be grouped into social isolation, loss of identity and role. Isolation comes in various forms both in relation to important community events and family as well as in daily life. It takes the visible form of disappearance of invitations to significant community and family events such as weddings, parties or outright orders to stay away. In the realm of daily life, the most common forms of social stigma are waning or disappearance of existing friends, and relatives to visit or lend or borrow common household implements and food items.

Another form of stigma is voyeurism. This is most frequently described in African countries as an increase in visits to people living with HIV, particularly once AIDS has set in, where the specific intent is to see how the person is progressing in their illness and report back to others and the community. This voyeurism, and the fear of it by people living with HIV and AIDS and their families, can lead to increased physical and social isolation of the person, as the protective or coping reaction becomes to keep all visitors away. Social stigma is also expressed through the taking away of certain roles, responsibilities, and social standing of those living with HIV



and AIDS within the family and community. As a result, HIV-positive people lose identity, power and respect.

People living with HIV are often assumed and judged to have transgressed some social norms of acceptable behaviour and are made to suffer as they are automatically associated with “social evils” (USAID, 2000).

- **Institutional stigma**

Institutional stigma refers to differential treatment within any broadly defined institutional setting that leads to a negative outcome for the person living with HIV/AIDS. This has to do mainly with loss of or inability to secure housing, livelihood, education and healthcare. It also includes losing access to future opportunities because an HIV-test is required to qualify for a job, scholarship, loan, insurance, or visas. Not only do all of these forms of stigma lead to reduced life chances for people living with HIV and AIDS, but they also often serve to visibly mark a person as having HIV, exposing him, or her to all other forms of discrimination and stigma (USAID, 2000).

Furthermore, the connection of stigma around HIV to historical racism and gender has developed a particular form of discrimination. Blame is often assigned to black people or to

women. Men blame women for infecting them and spreading the virus (Leclerc-Madlala, 1997, 2002). In couples, it can lead to violence against the woman or her exclusion from the home (Strebel, 1993). Stigma around the disease often attaches itself to existing stigmatisation frameworks (Sontag, 1988), for example, in South Africa, AIDS has been associated mainly with black people and women.

However, a number of studies have found a significant number of respondents who want people living with HIV (PLWH) to be identifiable, separated from the rest of the population, or excluded from the contact in school work and social institutions (Mathews, Kuhn, Metcalf, 1990).

Reports of stigma are enormous, extending even to the health professions. For example, the AIDS Law Project reported that the Health Professions Council of South Africa did not act against 28 doctors who breached patient confidentiality. The patients were mostly domestic workers. Their employers had been told of their diagnosis and many of whom were eventually dismissed (Altenroxel, 2001).

Some health professionals have refused to treat people with AIDS, on the grounds of possible risk infection (Krautkramer, 2000).

#### **2.5.4 Denial**

While different nations face different challenges as they confront HIV/AIDS, most HIV-positive people go through a phase of denial. As a defence mechanism, denial is an important protective mechanism because it temporarily reduces emotional stress. However, it could lead to the failure to take risk-reduction steps by practicing safer sex. People nationwide must understand that AIDS here at home is not over. Until such denial is diminished, HIV will continue to spread, with each new infection adding to the already immense human and economic toll. The fact is we do not have a cure for HIV. It is a devastating disease. (<http://www.psb.org/pov/pov2003/stateofdenial/special-us>.)

#### **2.5.5 Anger**

HIV-infected individuals are often very angry with themselves and others, and this anger is sometimes directed at sexual partner/s, at his or her past risky lifestyle, at themselves for not taking proper precautions, at the unavailability of cure for AIDS and because of the uncertainty of their future. They are also angry with those who infected them and with societies' reaction of hostility and indifference. People with HIV/AIDS may feel as though their normal lives have been ended because they must plan for medication appointments. This may lead to financial hardships, even if an individual has medical coverage. Also, dealing with multiple losses may lead to feelings of guilt, helplessness,

hopelessness, rage or emotional shutdown. Physical weakness and pain can also diminish the ability to cope with psychological stresses. (<http://www.aegis.org>).

#### **2.5.6 Fear of violence**

Some researchers have suggested that disclosure of HIV-positive status may provoke violence in intimate relationships (Glenen, 1997; Zierier, 1997). The kind of violence that can emanate can be physical or emotional combined with verbal abuse. For example, in a study conducted by Gielen (2000); she found that 12% of the HIV-infected women included in her study in Baltimore, USA, they reported fear of violence as a barrier to disclosure.

Therefore, people living with HIV may need a great deal of support to deal with the issue of violence around disclosure.

Of those whose infection status became known to others, many suffered direct violence at the hands of their families or community. Gugu Dlamini, a South African woman, was ruthlessly murdered by neighbours soon after she revealed her HIV-status as part of South Africa's commemoration of World Aids Day.

Women known or thought to be infected may also face abandonment by their families, eviction from their homes, and dismissal from their jobs. Gender-based violence is not only physical; it is also psychological violence (The Body, March 3, 1999).

### **2.5.7 Fear of upsetting family members**

In a study conducted by Yoshioka in the USA, it was found that among HIV-infected men, there were three major barriers to disclosure of HIV status to family members including:

- protection of family from shame
- protection of family from obligation to help
- avoidance of communication about highly personal information

In addition to the above, HIV-infected people also feel that they have lost their ability to care for themselves and their families and they fear the loss of their jobs, friends and family.

The above discussion has explored some of the theories about the origins of HIV/AIDS which are numerous and varied. It has also included the literature reviewed on the clients that have publicly declared their HIV-status, including their personal experiences, the psychological impact of HIV on families, the individual, or affected children as well as the common barriers to HIV/AIDS disclosure.

The following discussion draws the reader's attention to the literature reviewed on the common myths that are associated with HIV/AIDS, the projected epidemic in South Africa, and specifically looking at the projected total and adult HIV prevalence rates in KZN, and projected deaths and orphans in KZN in the year 2010.

## 2.6 Myths about HIV/AIDS

In every culture, rumours and myths exist about HIV/AIDS based on fear, denial, or misinformation. Common misconceptions can hamper people's abilities to protect themselves from infection and may lead to increased stigma and prejudice against people with HIV. Some of the most common myths are listed hereunder (Achmat, 2003):

- Myth

*Aids is a disease of gay white men in South Africa.*

Reality - Since 1991, research indicates that there have been more heterosexuals infected than homosexuals and the disease has spread among all race groups.

- Myth

*Aids is a disease of black people in South Africa.*

Reality - As we would expect, in terms of absolute numbers, there are many more black people infected than other race groups. But there is evidence that AIDS is spreading through all groups in South Africa and is breaching barriers.

- Myth

*HIV has spread so far that prevention efforts are irrelevant.*

Reality - Prevention efforts must remain a priority because:

- 1) Even in the worst affected areas where up to 35 per cent of the community are infected, at least 65 per cent are not and can remain uninfected.
- 2) Each year a new generation becomes sexually active and they can be educated to take precautionary measures.
- 3) In parts of South Africa, HIV prevalence is low.

- Myth

*Most of the population will inevitably be infected.*

Reality - As with all diseases, there appears to be a natural peak in HIV. Some people will not be at risk; some will be lucky, some will change their behaviour as they see others dying around them. Thus, the overall adult HIV prevalence rate is unlikely to exceed 30 per cent in South Africa, although some segments of the population and some regions will experience higher rates of infection.

- Myth

*I can be cured of AIDS if I sleep with a virgin.*

Reality - This is an urban legend doing the rounds in South Africa, which illustrates just how desperate the epidemic has made people

feel. South Africans need to work towards dispelling this dangerous myth that having sex with children/virgins will cure one of HIV/AIDS (Mc Clain, 2002).

- Myth

*African Society has always been promiscuous, and this is the driving force behind the AIDS epidemic in South Africa.*

Reality – As in the West, sexual patterns have changed as a result of a multiplicity of factors. In South Africa, social upheaval rather than sexual liberation may have been responsible for an increase in the numbers of sexual partners. But, there is no evidence to prove this (Human & Rousseau Tafelberg, 2000).

- Myth

*HIV is the same as AIDS.*

Reality – In fact, this could not be further from the truth. HIV is a virus and AIDS is a collection of illnesses. Knowing the difference between the two is a very important part of understanding both.

- Myth

*People above the age of 50 do not get HIV.*



Reality – People over 50 make up a rapidly growing segment of the HIV population.

- Myth

*I have just been diagnosed ... I am going to die.*

Reality – This is the biggest myth of all. People are living with HIV longer today than ever before. Medicines, treatment programmes and a better understanding of HIV allows those infected to live normal, healthy, productive lives ([Http://www.aids.about.com/cs/aidsfactsheets/tp/hivmyths.htm](http://www.aids.about.com/cs/aidsfactsheets/tp/hivmyths.htm)).

- Myth

*Condoms don't work because the virus can pass through the latex, and anyway they fail.*

Reality – The virus cannot pass through the latex. If condoms are used properly, consistently, and are SABS (South African Bureau of Standards) approved, they provide close to 100 per cent protection (Human & Rousseau, 2000).

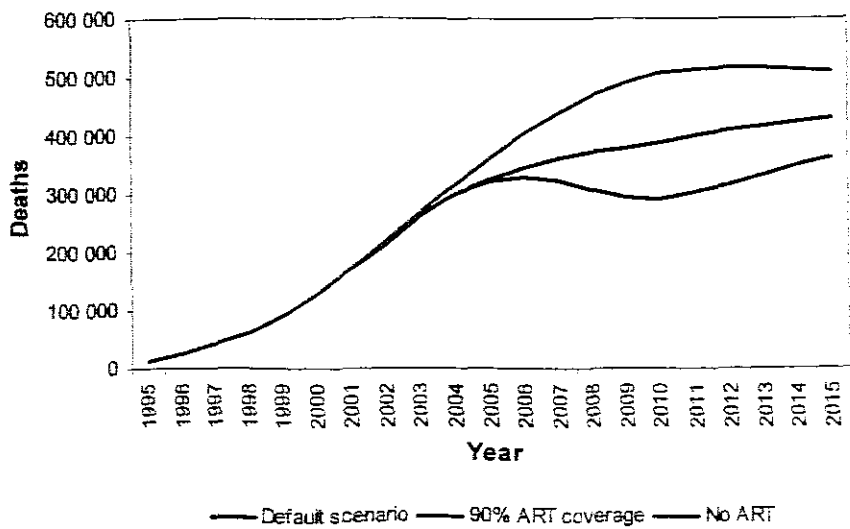
As a result, educational programmes aimed at sensitisation, reduction of vulnerability to HIV/AIDS, and the prevention of the spread of HIV/AIDS, are important to all communities around South Africa.

Also, in line with what Dr Mangosuthu Buthelezi said in the literature reviewed for this research, it is important to form a long-term strategy to defeat HIV/AIDS.

Such a strategy should include partnerships between the infected/affected, the private/public sectors and international organizations in the fight against the epidemic, which is projected in the next section.

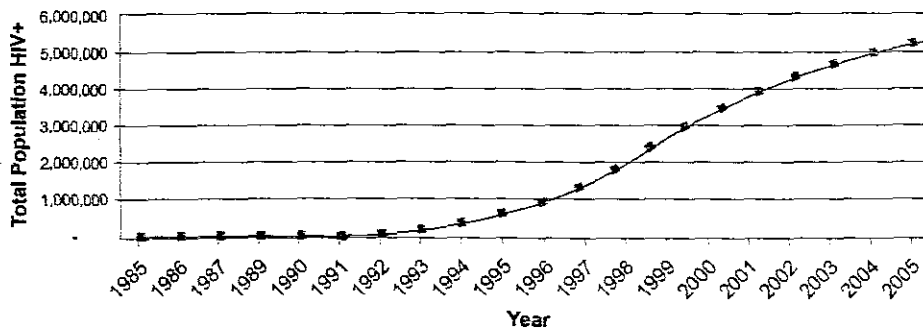
2.7 Projecting the epidemic in South Africa

The impact of the epidemic and death is being felt by families, the public health service, and some private sector firms. Graph 2.1 below projects that by 2010, there are likely to be roughly 388 000 AIDS deaths per annum rather than the 505 000 that would have been expected if no ART programmes had been introduced. In the default scenario, it is assumed that ultimately only about half of South Africans who need to commence ART will be able to access it.

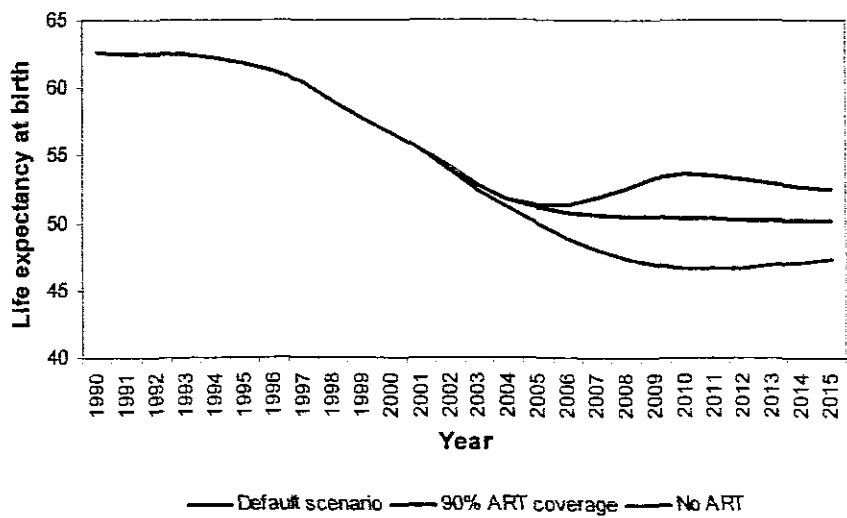


**GRAPH 2.1 – Projections of AIDS deaths by level of coverage of national ART programme, ASSA 2003**

The Actuarial Society of South Africa has developed the ASSA AIDS and Demographic models that are widely used to estimate current and future HIV and AIDS related statistics. Graph 2.2 below shows total numbers of HIV positive South Africans over time.

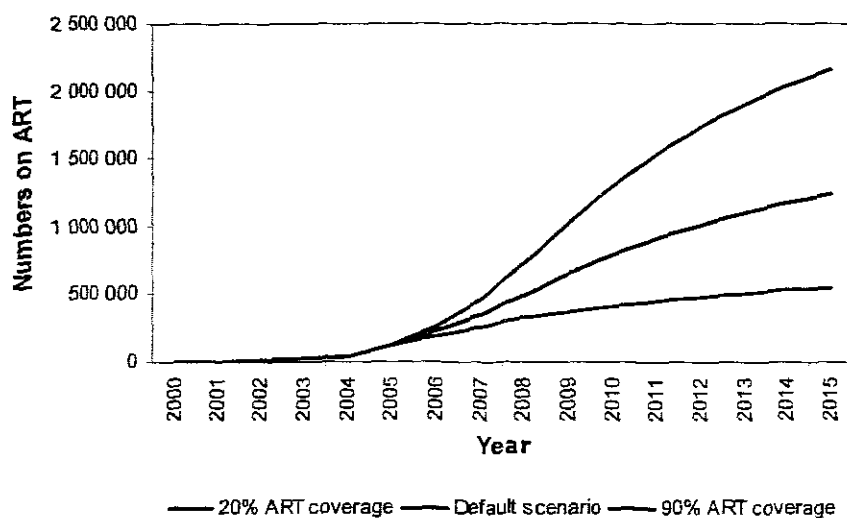


**GRAPH 2.3** – Projected HIV impact on life expectancy by levels of coverage of national ART programme, ASSA 2003



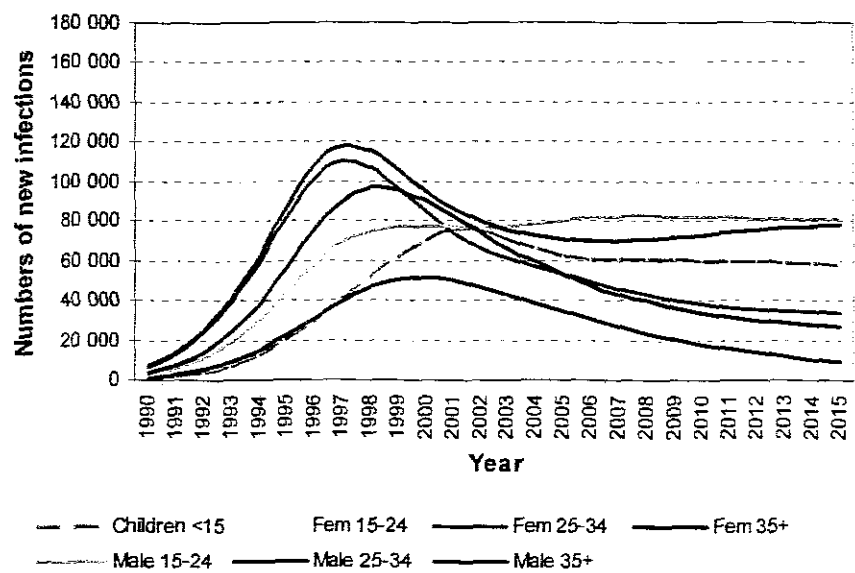
Based on scenario of ART being made available so that half those who need treatment would by 2010, life expectancy at birth is expected to fall a little above 50 years by 2010 (48years for men and 52 for women) and the level off at around this level.

**GRAPH 2.4 - Projected numbers receiving treatment by level of coverage of national ART programme, ASSA 2003**



Graph 2.4 suggest that in 2006 around 711 000 people are in need of ART (i.e. have experienced AIDS –defining symptoms).The number of people that will be receiving treatment is a function of the how successful the rollout is, and how successful ARV’s are extending life.

**GRAPH 2.5** - Projected number of new infections by sex and age group,  
 ASSA 2003



Graph 2.5 above shows the incidence of infections as one of the most important indicators of the progression of the epidemic that needs to be monitored, particularly in the more mature stage of the epidemic. The graph shows the projected number of people who are expected to be newly infected with HIV each year, using the default scenario. From the graph, it is clear that the 15- 24 year age group, and particularly women, contributes high numbers of new infections. Empowerment of young women could be an important strategy in limiting the spread of the epidemic.

## **2.8 Political Issues relating to HIV/AIDS in South Africa**

On the 28<sup>th</sup> of October 2006, the South African Government announced a dramatic reversal of its approach to the country's HIV/AIDS crisis, by promising increased availability of drugs and endorsing the efforts of civic groups battling the disease. Prior to government's decision, activists fought a prolonged legal battle that forced Thabo Mbeki's government to distribute the life-saving ARV drugs through public health services. Initially, the president had questioned that AIDS was caused by HIV, and said it was not certain that ARV drugs were safe and effective. He denied knowing anyone who had died of AIDS, despite several prominent South Africans succumbing.

Again, confusion over what is effective Aids treatment was spread by Health Minister Manto Tshabalala –Msimang, who adamantly promoted a diet of beetroot, lemons and garlic as alternative treatment. At the Toronto Aids conference, she sparked uproar with a South African government display of the fruits and vegetables but no ARV's. The South African government's position on Aids was denounced as "wrong, immoral and indefensible" by Stephen Lewis who is the United Nations' top official on AIDS. Supporters of the ruling African National Congress such as trade unions have criticised the president's policies and the resulting shortage antiretroviral drugs. Several factors convinced Mbeki to change his policies on Aids. (Guardian Newspaper, October 28, 2006).

## **2.9 Résumé**

The literature reviewed gives more insight into the argument of this thesis. Theories about the origins of HIV/AIDS are numerous and varied. The importance of publicly disclosing one's HIV-status was demonstrated by different individual experiences. The psychological impact of HIV/AIDS, the myths about HIV/AIDS and the common barriers to disclosure also formed part of the literature reviewed. The next chapter presents the methodology to be followed in soliciting the data needed to answer the question which initiated this investigation.



## **CHAPTER THREE**

### **RESEARCH METHODOLOGY**

#### **3.1 Introduction**

The aim of this chapter is to illustrate the methodology followed by the researcher in soliciting the data needed to accomplish the aim and objectives of the present study. As stated in Chapter one, the objectives of the study were:

- 1 To reveal to the public a conducive environment for disclosure
- 2 To establish the importance of and to assess the psychological impact of disclosing one's HIV-positive status
- 3 To empower HIV-positive individuals to seek appropriate support and counselling

Ultimately, the aim of the study is to provide the researcher with an understanding of the issues of disclosure that would form a basis for the development of a programme related to HIV/AIDS disclosure (later) based on the findings of the study. This chapter is a layout of all the procedures followed to accomplish the aim and objectives.

## **3.2 Sampling**

The sample for the present study comprised of 30 HIV-positive men and women belonging to the support groups that are based at one of the hospitals in KZN. All the participants who participated in the study were aware of their HIV status, had received post-test counselling and had disclosed in the group. However, some had not disclosed to family members and the community.

After informal contacts and conversations with the officials at this hospital; they were very receptive to the idea of research being conducted on HIV-positive individuals who belong to the support group. Thus, the researcher was able to select a purposive sample of N=30 (15 males and 15 females). This sample was selected from a population of 133 HIV-positive support group members, who are unemployed, and stay in the local community. In selecting the sample of 30 participants from a population of 133 HIV-positive support group members, the random sampling procedure was used. Each and every support group member out of (133 members), was assigned a number so that the researcher could not be biased by labels, names, or any identifying criteria. This means that each and every member of the support group had an equal probability of being selected for the sample. All numbers were put on a fishbowl, thoroughly mixed, and a sample of 30 participants was drawn randomly. (Bailey, 1994).

Informed consent was obtained from all participants.

The nature and purpose of the study was explained to the participants. The right to privacy, voluntary participation, anonymity and confidentiality were maintained. The researcher further undertook to adopt a “value-free” approach and to present the results and findings as objectively as possible (Babbie, 2003). In addition, the researcher further explained to the participants their rights in respect of the following points:

- \* A description of the potential benefits to the participants
- \* An offer to answer any inquiries concerning the study at any time (the researcher gave the participants her office numbers, physical address and telephone numbers.
- \* The participants were informed that they are free to withdraw their consent and to discontinue participation in the present research at any time without prejudice.
- \* An assurance that any information derived from the research project which personally identifies the participant will not be voluntarily released or disclosed without the participant's separate consent.
- \* Assurance was also given to the participants that if the study design or the use of the collected information is to be changed, they will be so informed and their consent re-obtained. (Bailey, 1994).

## **Voluntary Participation**

Research requires people to reveal personal information about themselves, information

that may be unknown to their friends and associates. Therefore participants must participate voluntarily (Babbie, 2003). In the present research, the participants were told that their participation is completely voluntary and that they could withdraw their consent and discontinue participation without any prejudice.

### **Confidentiality and anonymity**

Confidentiality and anonymity concerns the protection of the participants' interest, well-being, and their identity, especially in survey research (Babbie, 2003). In order to maintain anonymity and confidentiality, the researcher requested the participants not to include their names and addresses in the questionnaires, but replaced them with identification numbers. A master identification file was created that linked the numbers to names in order to later permit the correction of missing or contradictory information, and was kept by the researcher.

## **3.3 Techniques for data collection**

The following tools were used to collect data.

### **3.3.1 The Questionnaire**

The Questionnaire consisted of two main sections: The biographical

inventory (Section A) and the individual needs exploratory questionnaire (Section B).

**3.3.1.1 Biographical inventory**

A biographical inventory was constructed. The following information was obtained from each subject:

- Identification number .....
- Age ..... Years ..... Months .....
- Level of education .....
- Marital status .....
- Employment status .....

**3.3.1.2 The needs exploratory questionnaire**

The needs exploratory questionnaire consisted of closed and open-ended questions. It was designed to elicit information concerning the definition of disclosure, the reasons for disclosing one's HIV-positive status, the reasons for not willing to disclose one's status to others, the positive benefits that an HIV-positive individual

experienced by disclosing his or her status, the circumstances under which the first disclosure occurred, the person(s) to whom first disclosure was made, and the aspects in which the environment in the support group differs from that in one's home and the community.

### **3.3.2 Focus group catharsis**

Both the questionnaire and focus group constituted needs assessment, which is exploratory research. Participants were divided into three groups of 10. Simple random sampling procedures were used to allocate participants to the three different groups. All 30 participants were each

assigned a number so that the researcher could not be biased by labels, names, or any identifying criteria. All numbers were thoroughly mixed and put on the fishbowl. The researcher then drew at random the first ten (10) participants which constituted the first group. The researcher further drew the next (10) ten participants from the fishbowl which constituted the second group. The last group consisted of last ten (10) respondents that remained in the fishbowl. The focus group served two purposes. Firstly, it served as a further needs exploration tool as well as for catharsis. Secondly, it served as an avenue for empowerment of the members as in Annexure C.

### **3.3.3 Procedure for data collection**

The present study is a participatory action research, which combined exploratory research and social action. The use of multiple methods is a plan of action that raises the psychologist, and other social researchers, above the personal biases that stem from a single methodology. By combining methods in the same study, researchers can partially, overcome the deficiencies that flow from one investigator or method (Denzin 1989). It also minimises the major threats to reliability and validity and increases confidence in the results and conclusions of the study.

The rationale for using participatory action research is that it uses all the conventional tools of research. Tools which acknowledge the value of the opinions and thoughts of all people, such as focus groups (HIV-positive support groups), in-depth interviews (like exploratory research) and participant observation tend to be more popular than structured interviews, questionnaire and simple observation. As a result, there is no one way of doing participatory research (Bless, Smith, Kagee, 2006).

Since participatory action research takes place in a “natural setting”, it has the following characteristics:

- 1 It describes the actions of the research participants in great detail and then

attempts to understand those actions in terms of their actions, own beliefs, history and context.

- 2 It encourages active participation of the people whom research is intended to assist.
- 3 Research is used as a tool to bring about social change, which is achieved through the democratic collaboration of the social researcher, community (i.e. support groups) and other parties (i.e. hospital officials at the selected research hospital).
- 4 Tools used, acknowledge the value of the opinions and thoughts of all people (focus groups that were formed from the support group, depth interviews and participant observation as already mentioned as the rationale for using participatory action research as well.
- 5 There is Action and Research taking place alternatively in an ongoing learning process for everyone involved as shown in figure 3.1.
- 6 There is no general formula.

Figure 3.1



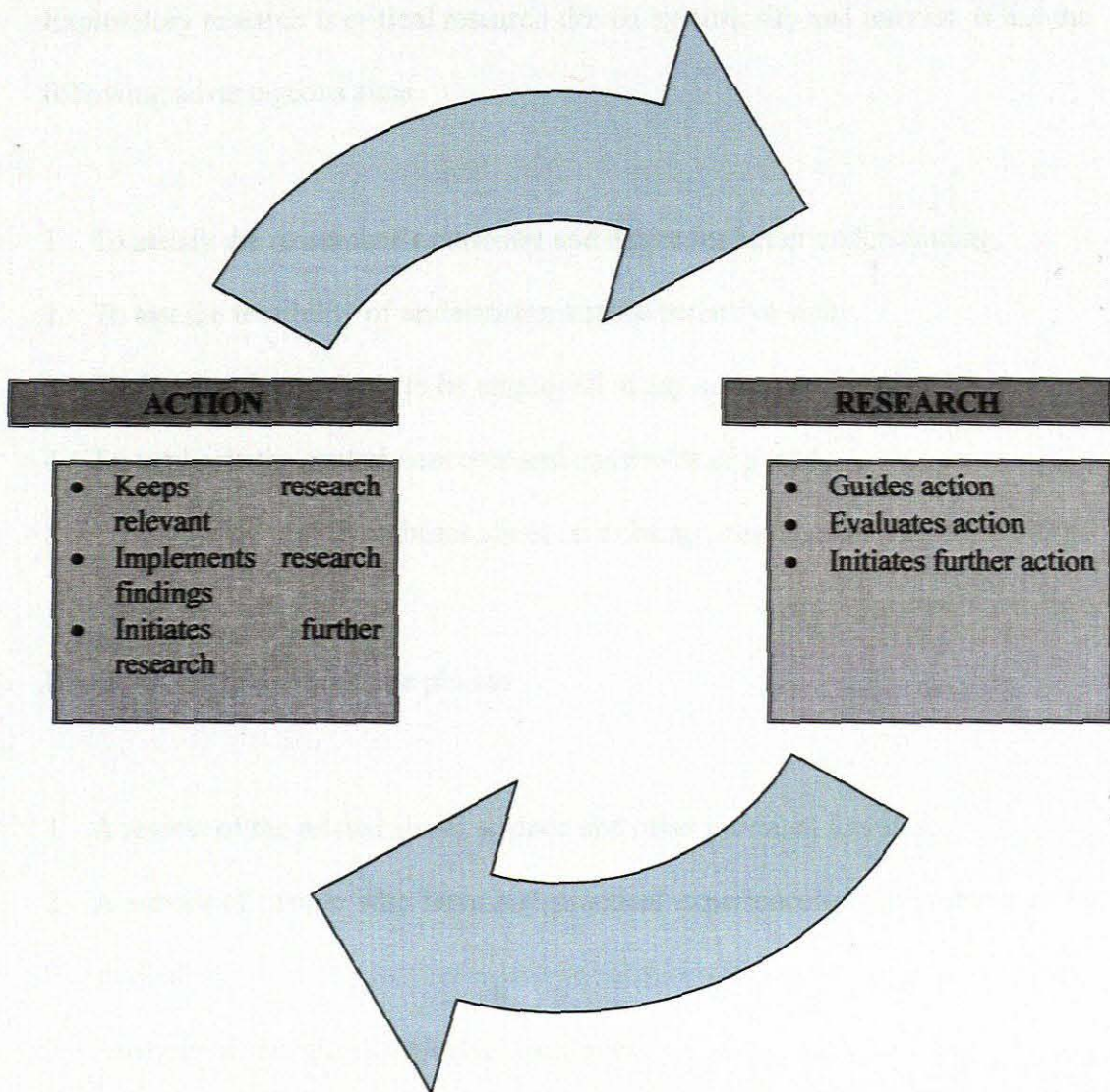


Figure 3.1

This cycle produced a process of ongoing learning and empowerment for all the participants in the study.

Exploratory research is critical research driven by curiosity and interest. It has the following advantageous aims:

- 1 To satisfy the researcher's curiosity and desire for better understanding.
- 2 To test the feasibility of undertaking a more extensive study.
- 3 To develop the methods to be employed in any subsequent study.
- 4 To explicate the central concepts and constructs of a study.
- 5 To determine new hypotheses about an existing phenomenon (Babbie, 2003).

It follows the following three phases:

- 1 A review of the related social science and other pertinent literature.
- 2 A survey of people who have had practical experience of the problem to be studied.
- 3 Analysis of 'insight-stimulating' examples.

Because exploratory research usually leads to insight and comprehensive data rather than the collection of detailed, accurate, and replicable data, it involves the use of in-depth interviews, and the use of informants.

Action taken was change oriented. The focus was on real intervention by the researcher for the purpose of changing the 'problematic' situation for the better. Action also helped the researcher to reflect on the results of the present study.

Both parties gained valuable knowledge, experiences, and attitudes.

The researcher gained first hand experience of problems encountered by the people - diagnosed as HIV positive and the effectiveness of different solutions which is extremely valuable in dealing with other communities (support groups).

A particular obstacle to well-being was removed as they were able to express their feelings in the presence of a professional psychologist. Members in focus groups sessions learned more about themselves, their problems and resources to empower them for future problem solving (Bless, Smith, Kagee, 2006).

### **3.3.3.1 Gaining Entry**

The social scientist (a psychologist) had no information available and set out to find out difficulties faced by the support group members. It should be mentioned here that the section at the research hospital that deals with the running of community psychology interventions, including the promotion of health and wellbeing, played a major role in introducing the researcher as a specialist that is able to provide both general psychological services, as well as specialist services in the area of HIV/AIDS. Thus, the researcher was able to gain entry and acceptance by the leader of the support group, who in turn introduced the researcher to the rest of the support group members. Informal discussions and conversations with members of the support group prior to conducting the actual study enabled the researcher to establish rapport with the support group members.

The researcher felt obliged to empower the support group while learning from them.

The researcher avoided patronizing the group by dictating what problems they were facing in relation to HIV/AIDS disclosure and barriers associated with disclosure as well as how members of the support group should go about finding solutions to their problems. At this stage, the researcher tried to establish a broad ethical framework based on mutual trust, within which they were going to work together with members of the support group.

Again, it was necessary at this stage to construct a formal action research contract with the support group members which outlines exactly what each party is expected to contribute to the research project and what each party can expect to gain from the project prior to collecting data for the study.

The following diagram contains an illustration of the contract that was agreed upon between the researcher and the support group members prior to entering the next phase of the research (Bless, Smith and Kagee, 2006).

**TABLE 3.1**

<b>Support Group</b>	<b>Researcher</b>
<p>To provide:</p> <ul style="list-style-type: none"> <li>• active participation</li> <li>• first-hand, practical knowledge of the problem on the ground</li> <li>• skills</li> </ul>	<p>To provide:</p> <ul style="list-style-type: none"> <li>• active participation</li> <li>• academic knowledge and theory</li> <li>• academic and research skills</li> <li>• skills training</li> </ul>
<p>To receive:</p> <ul style="list-style-type: none"> <li>• a solution to their particular problem</li> <li>• a solution for future similar problems</li> <li>• skills to solve future problems</li> <li>• skills training and access to resources</li> </ul>	<p>To receive:</p> <ul style="list-style-type: none"> <li>• a general solution to similar problems applicable to a range of similar communities</li> <li>• increased understanding of the problems faced by some communities</li> <li>• development of theory</li> <li>• publication</li> </ul>

### 3.3.3.2 Needs exploration

The needs exploration exercise informed the researcher in great detail analysis of particular challenges facing the support group and the available resources with which those challenges could be met. This involved filling in of the questionnaire as well as focus group catharsis.

- 1 Assessment of the extent to which members of the support group actually understand the concerns and needs of all people within the group.
- 2 Assessment of whether they put their scarce resources to good use.
- 3 Identifying problems leads to:
  - 1 Understanding of underlying causes (focus group)
  - 2 Solutions becoming apparent (as per attached established intervention programme) ANNEXURE A

The results of this research were compiled and made available to the authorities at the research hospital and to members of the support group and there was a follow-up session in order for them to receive verbal feedback (Bless, Smith, Kagee, 2006).

### **3.3.3.3 Implementation**

It is during this phase that action and research takes place.

ACTION	RESEARCH
<ul style="list-style-type: none"><li>• Action designed (Annexure A)</li><li>• Action taken (Annexure A)</li><li>• Results of the action were assessed.</li><li>• Evaluation of the action (research)</li><li>• If necessary, designing of the ACTION.</li></ul>	<ul style="list-style-type: none"><li>• Resources &amp; needs were systematically assessed.</li><li>• Necessary information to guide appropriate action was gathered.</li><li>• This informs the ACTION which the action research partners would undertake together.</li></ul>

### Strengths of participatory action research

- \* It helped members of the support group to explore their own needs and resources in a systematic manner.
- \* It was concerned with solving particular problems facing communities.
- \* It helped individual members of the support group to learn skills and gain access to resources so that they can function more effectively in future.
- \* It provided a way of spreading the understanding gained through research to the support group.
- \* It led to the understanding of the HIV positive person within a broader social context.
- \* It aided communication between the researcher and the support group members.

\* It shook the “ivory tower” of the present researcher (a counselling psychologist) and made her work directly beneficial to society.

### **Limitations of participatory action research**

\* Extraneous variables are difficult to control, for an example, they might have received extra help from somewhere during the research.

\* The close relationship between the “researcher” and “participant” makes it difficult for the “researcher” to be objective and the research is, therefore, vulnerable to all kinds of bias.

\* The necessary narrow focus of research (to a particular community with a particular difficulty) prevents the researcher from generalizing findings to other communities (Bless, Smith, Kagee, 2006).

### **3.3.4 Techniques for data analysis**

The biographic inventory was summarized quantitatively using percentages.

#### **3.3.4.1 Qualitative data**

In order to obtain clarity from the participants, the information narrated by the participants in focus groups was summarized and categorized into themes and then analysed along the lines suggested by Giorgi (1995), who suggested the following steps



in this method:

- \* Narratives obtained from each participant were transcribed verbatim and translated into english for analysis.
- \* The information narrated by the participants was read with a psychological perspective, and themes began to emerge.
- \* The actual content of the participant's narratives was considered appropriate and hence retained in the text.
- \* The researcher then synthesized all transformed meaning of units into statements regarding the participant's experience. Details of themes that emerged and scored are reported in the next chapter.

### **3.4 Résumé**

The procedures followed in the present study have been laid out, including the questionnaire that was used to collect data. The main strength of this study is that it encouraged self-expression from the HIV-positive support group members. The next chapter presents the analysis and discussion of the results.

## **CHAPTER FOUR**

### **PRESENTATION, ANALYSIS AND DISCUSSION OF RESULTS**

#### **4.1 Introduction**

This chapter presents the data collected for this study along with responses about significant findings. The responses from biographical data are presented and discussed briefly. Narratives obtained from each participant were transcribed verbatim and translated into English for analysis. Qualitative analysis focused mainly on themes that emerged from the narratives.

#### **4.2 Presentation of data**

##### **4.2.1 Biographical information**

The sample consisted of (N=30) participants, 15 (50%) men and 15 (50%) women. The mean age in years was 31 (range =18-50 years). Ninety percent of the samples were from a rural background and 10% from an urban background. Sixty-four percent were unmarried, 24% were cohabiting and 12% were separated.

Education levels are relatively low with over 80% of the participants with less than grade seven as their level of education. Forty-seven percent, almost half of the participants reported more than one sexual

partner over the past 12 months prior to the current research. All participants (N=30) were unemployed. This could be because employed people have medical aids and receive their ARV treatment through their private doctors. Also, the support group meets during working hours.

#### **4.2.2 Disclosure issues**

##### **4.2.2.1 Definition of disclosure**

When the participants were asked the question, “how would you define disclosure?” two types of themes emerged. In the first theme which was reported by seventy percent (70%) of the participants, (65%) females and (5%) males, defined disclosure as a positive act and considered sharing of emotions and HIV-related information as an important part of coping with the illness. It was also the sharing of private or secret information with others.

In the second theme which was reported by thirty percent (30%) of the participants (25%) females and (5%) males, defined disclosure as an undesirable act but occurred because the participants felt that there was no other choice. Disclosure in these participants was accompanied by a sense of helplessness.

#### **4.2.2.2 Reasons for disclosing one's HIV-positive status**

There were two themes that were revealed by the participant's response to the question, "What were the reasons for disclosing your HIV-positive status?" Seventy percent (70%) of the participants reported that they had chosen to disclose to elicit various forms of support, which included both financial and emotional support. Fifteen percent (15%) reported that they disclosed only for financial help. The need to gain medical care and counselling was reported by fifteen percent (15%) of the participants. A small number of ten percent (10%) felt that it was their responsibility to disclose, as their partners needed testing.

This finding is supported by the social support theories who distinguished between three basic types of support that appeared most important for people with chronic illnesses: informational, emotional and tangible.

- Informational support helps people stay grounded in the realities of their condition.
  - Emotional support is offered through affection and empathy.
- Both informational and emotional support has been shown to reduce the distress of having a chronic illness, including HIV/AIDS.

- Tangible support is also important for people with HIV/AIDS, particularly at the later stages of the disease, when they need help with meals, housekeeping, shopping, transport and other tasks of daily life.

This finding is also supported by research conducted by Duffy (1994) who found that disclosing an HIV-positive status to another individual is an important contributor to one's perceived social support. The interrelated relationship between social support and disclosure influences psychological adjustment. Moneyham and Seal (1996) for example, found that HIV-positive individuals who share their status with a family member or their partners demonstrate significantly lower levels of emotional distress than those who choose to keep their status secret (Armistead & Tanenbaum, 2001).

#### **4.2.2.3 Reasons for not disclosing**

Concerning the reasons for not willing to disclose one's status to others, hundred percent, 30 (100%) of the participants overwhelmingly agreed that the social stigma, isolation, and ridicule that people with HIV/AIDS experience, are the reasons for not disclosing their HIV-positive status. Participants were asked to supply examples of "bad treatment" faced by people living with HIV/AIDS. Male participants reported examples of social isolation (70%), gossip (50%), rejection

from the home (33%), rejection from the community (20%), and verbal abuse (15%). Female participants reported social isolation (65%), rejection and discrimination (40%), gossip (50%), and verbal abuse (30%). Some responses were: “They treat me like a dog,” “they refuse to let me share their pots and dishes with them,” “they look at us with disgust.” Nearly 60% percent of the sample reported fears related to society’s attitudes towards the illness.

Disclosure of HIV infection can lead to important social support that can mitigate the negative effects of stress (Hays, 1993). Conversely, hiding one’s status may not only preclude HIV-related social support and its attendant benefits but may also have direct negative effects of disease progression for HIV-positive individuals (Cole, 1996).

#### **4.2.2.4 Positive benefits obtained by disclosing**

It is interesting to note that some of the themes that emerged when the participants were asked the question: “What were the reasons for disclosing your HIV-positive status” also came up here. Eighty percent (80%) of the participants reported receiving financial and emotional support as positive benefits that they obtained by disclosing the HIV-positive status. Twenty percent (20%) reported that they received financial support from friends and relatives. Thirty percent (30%) reported receiving emotional support and acceptance by members of the support group.

Disclosure of serostatus has implications for social support, which in turn, may affect psychological well-being. Disclosure or knowledge of serostatus has often been positively related to social support (Kadyshin, 2000).

#### 4.2.2.5 Negative effects of disclosing

Regarding the negative effects resulting from disclosing one's HIV-positive status, fifteen percent (15%) females and eighteen percent (18%) males had already felt discriminated against by relatives. This proportion was similar for discrimination by friends, fifteen percent (15%) females and eighteen percent (18%) males, and it was slightly higher for discrimination by sexual partners twenty-two percent (22%) females and thirty-six percent (36%) males.

Types of Disclosure	Frequency	Percentage
Voluntarily with my consent	18	60
Disclosure occurred without my consent	7	23
Disclosure had to occur as there was no other choice	5	17

**TABLE 4.1 Circumstances under which disclosure occurred**

Table 4.1 revealed that (60%) of the participants, reported that disclosure occurred voluntarily with consent. While (23%) of the participants reported that disclosure occurred without the participant's consent. Only (17%) of the participants reported that disclosure had to occur as there was no other choice. Participants reported the following when disclosing or describing the type of disclosure:

"I told my family because I was sure that they would take care of me and be there for me."

"They are my relatives and I felt it was important for them to know about my status."

"I had to tell my partner because he also needed to be tested."

One participant captured this as follows: "I just tell people up front. Do you want to come to my room? Listen here, I'm HIV-positive, that's the way it is."

Disclosure in these participants was accompanied by a sense of helplessness: "I am staying with them; I have no choice but to tell them." "They are my family members, and I rely upon them for financial support, hence I have to let them know."



The analysis of the reasons for disclosure in this study revealed findings similar to those found in a study by (Simon et al., 1995), with most participants reporting reasons such as expectations of emotional and material support from others.

Concerning worries regarding disclosure and reasons for non-disclosure, these are found to be linked to each other and overlapping. Worries, about stigmatisation, social isolation, rejection and discrimination, resulted in non-disclosure.

These findings are supported by studies conducted by (Bharat & Aggleton, 1999), who found that felt or perceived stigma and discrimination are at times more powerful than enacted stigma and discrimination, in discouraging people from being open about their HIV-positive status and in accessing support and treatment.

	Frequency	Percentage
Parents/siblings/spouse	10	33
Relatives (in-laws, cousins, uncles)	4	13
Professionals only	8	27
Religious people only	5	17
Neighbours	4	13
Community	4	13
Support groups	7	23

**TABLE 4.2 Persons to whom disclosure occurred**

Table 4.2 shows that in 33% of the participants disclosure occurred to (parents, siblings or spouse) while 27% disclosed to professionals only, and 23% of the participants disclosed to support groups. Only 17% disclosed to religious people and 13% disclosure occurred to relatives such as cousins or uncles, another 13% disclosure occurred to neighbours or community.

It should be noted here that the total percentage to whom disclosure occurred, adds up to more than 100% due to the participants giving multiple responses.

#### **4.2.2.8 How do aspects of the support group environment differ from the home and community**

With regard to listing of the aspects in which the environment in the support group differs from that in the home and community, five key themes emerged. These themes were:

- (i) "Talk about it in order to educate and prevent the spread...."
- (ii) "Gaining support and coping with the illness...."
- (iii) "Need to know and be empowered...."
- (iv) "Places of healing...."
- (v) "Love and acceptance...."

One participant said the following as captured in the needs exploration questionnaire:

“As my health was beginning to deteriorate, I got scared of being alone. As a result, I joined the support group. In the support groups, I found a whole circle of new caring friends. I found my life being transformed. I met people diagnosed with HIV, and was shocked to find out that they were actively alive. These other people became my role models for living with HIV. I also found the motivation and support to do the work of healing. I then became a role model for others, as I discovered the joy of being accepted and also discovered that life with HIV/AIDS is easier when the burden is shared with supporting groups.”

All participants in this study 30 (100%) agreed that HIV/AIDS education is necessary and there was no expressed opposition to HIV/AIDS education per se. This confirms the findings of James and Glover (1993) who found that 92% of the participants in their study felt that AIDS education could successfully prevent the spread of AIDS. Most participants felt that unless some interventionist programmes are instituted, there would be “many deaths” and “many innocent victims.” This finding indicated a strong positive belief in the value of education as a means of changing attitudes towards HIV/AIDS.

#### **4.2.2.8.1 Sufficient information about HIV/AIDS to educate children**

The participants also felt that the parents should have sufficient information about HIV/AIDS to educate their children at home. The provision of information including, abstinence from sexual intercourse, being faithful to one's partner and the use of condoms as very essential. This type of education is not provided at home but only received in the support groups. Research by Selvan, Ross and Kapadia (2001) revealed that when parents are better educated and informed, adolescents are less likely to be sexually active.

#### **4.2.2.8.2 Gaining support and coping with the illness**

As opposed to the home and the community, the participants overwhelmingly felt that in the support group environment they receive care and support from other HIV-infected individuals. They also learn life skills and how to cope with the virus.

According to the participants, it is not only about AIDS, because if you have the virus, you sometimes have other emotional problems, like depression because you know you are going to die. We need to know about this and how to help people who feel that way.

#### **4.2.2.8.3 We need to know and be empowered**

All participants (N=30) expressed a need for different kinds of information. They also expressed the view that they know that the virus is there, but, in the support groups, they get told what to do about it. They also reported that within the support groups, they feel more responsible, useful and empowered rather than to be frustrated by the community.

#### **4.2.2.8.4 Places of healing**

All participants (N=30) reported that the environment in the support groups provide people with HIV a relaxed and informal place to share their experiences and build new friendships. As they face changing social supports and financial situations, they become frightened and worried. When others reject them and ill-treat them, they become depressed, angry and isolated.

In support groups, they learn that they are not alone and that they can build a new life. One of the participants had this to say about the environment in the support group:

“I am able to share with these people my deepest secrets and still be loved. When I first became sick, it was the support group and not my family that gave me strength to keep going. I was at the point of committing suicide, but members of the support group saved my life, so I know how important it can be

for others. The support group environment is seriously a place of healing.”

Support groups also provide a non-judgmental environment where people with similar experiences vent their feelings.

#### **4.2.2.8.5 Love and acceptance**

All participants (N=30) in this study reported that the environment in the support groups is a major source of love and acceptance. Participants reported that in support groups they gain acceptance, support, intimacy, and close friendship groups. They also reported that they benefit skills to deal with their issues, including their feelings about fear, changed social conditions, health concerns and obsessional thoughts. Support groups help them meet the challenges of social isolation, how to cope with the various intra personal stressors, and how to reduce stress and burnout.

### **4.3 Data from focus groups**

From the in-depth interviews in the focus groups, the following themes emerged as account of emotional observations made by members of the support groups. These emotional observations are discussed as cases that were captured during the interviews.

### **4.3.1 Isolation**

The participants reported that being HIV-positive is extremely isolating. It became evident during the interviews that most participants are afraid of the virus.

They expressed the feelings that being diagnosed as HIV-positive lead to their abandonment by friends and family members. In some instances, co-workers may not even want to work or eat with them.

One of the participants had this to say when she asked her brother to take her to hospital:

“I was seriously ill and asked my brother to take me to the hospital. My brother refused and told me that I was hopeless. He told me not to bother him or other people, and does not want to waste his money on me because I was going to die.”

Another participant reported her encounter with a street vendor by saying, “I asked the vendor to sell me a cup of juice to drink, in response, the vendor said, “If you drink from this cup other people who see you drinking from it wont dare want to use the cup again. So, take the drink in a plastic bag. Is it okay!”

Other participants stated that people living with HIV and AIDS have to deal not only with medical problems, but also with social and emotional issues. Some of them stated that they worry about what will happen to their children and spouses when they become seriously ill or die.

Participants indicated that they feel sad, tearful, angry and anxious. Sometimes, as they explained, “we lose hope in the future.” These feelings sometimes become so strong that one cannot carry on with day to-day activities.

On the other hand, some were saying: “knowing that they have a fatal illness, gives them courage to focus on what is important to them. Being HIV-positive has given them the opportunity to change or walk away from situations that are unpleasant or unhealthy.”

#### **4.3.2 Social stigma**

Some participants from the support group had the following experiences to share with the researcher:

One participant described her experience: “I have a serious problem with my family, especially my father. He refuses to let me participate in any kind of social life. He always likes to say to me, “Please, do not show your face to the neighbours and the community, and do not come



close to our relatives.” “To me, this is a damaging expression of social stigma against me.”

Another participant explained that, “members of her community asked her to terminate all contacts with her childhood friends because people told her that she is HIV-positive and should stop spending time with her friends.”

Another participant explained: “Members of my community avoided me by not shaking hands with me. They turned their faces, and show their backs and do not exchange verbal greetings or would not sit with me in places of social gatherings.”

Another participant who was concerned about social stigma shared her experience as follows:

“Last time a ceremony was conducted in my neighbourhood and when I helped with the peeling and chopping of the onions among other things, I was, however, not allowed to participate as one woman said to me, “just do yourself a favour by resting as the onion will soon burn your eyes.”

As a result, they are frequently viewed as irresponsible and immoral and therefore not fit to command respect, hold positions of responsibility and participate in decision making.

On the issue of verbal stigma, a member of the support group shared her experience by saying: "Let me tell you from my experience, in our community, I am the only one who is suspected of having the virus. On the contrary, many men are but funny enough nobody seems concerned to talk about the infected men. What the community does is just to spread gossip about my name."

The researcher also observed the expressions of verbal stigma which were expressed through insulting, mocking, cursing and threatening to those living with HIV and AIDS. Expressions of verbal stigma included blame, and shame often through scolding or judgemental statements indicating the HIV/AIDS infected people deserve what they have since they got what they wanted.

Participants also expressed the views that people with HIV and AIDS are blamed for becoming infected with the virus because of their irresponsible behaviour, and for bringing shame to themselves, their families, communities and being a burden to both their families and communities.

According to the participants, the community believes that people get infected with HIV and AIDS due to their deviant behaviours when they have sexual contact with more than one partner. They think that a person who gets infected with HIV and AIDS is a promiscuous person.

Another participant expressed having lost hope in everything by saying: "Being in such a state as I am how I could be married even if I wanted to? If I could be given another chance to begin my life again, I would certainly be grateful. As it is now, I cannot have a wife. My economic losses and present situation can never be regained, and my body is tired and unhealthy." This participant also expressed feelings of helplessness and hopelessness.

Another account given by one of the participants was captured as an extract that follows: "In support groups, we meet others who have had similar experiences. They learn that they are not alone and that they can still build a new life." Further on, he said: "I could share with the support group my deepest secrets and still be loved and accepted." Usually in support groups one gains acceptance, support, be nurtured and intimacy from close friendship groups, and or religious groups.

In the support group, one can also benefit from special support to deal with their issues including their feelings about fear, grief, health concerns, social conditions, and obsessional thoughts. Groups enable us to discuss our concerns with others by sharing the same experiences and emotions and to work out complex feelings of worthlessness, frustration or alienation."

The following extract also captures the consequences of disclosing one's HIV-positive status and becoming a member of a support group: "My valuable experiences, as well as the friendships and knowledge gained through the support group is far important to set a price on. The sharing of practical HIV treatment and information gained from the support group members has also helped to advance the way I live with HIV for ever increasing amounts of time. The gratitude I feel for the people who make this possible is immeasurable, support groups are places of healing."

### **4.3.3 Other emotional observations:**

#### **4.3.3.1 Anger**

Some participants were angry at themselves and others by not taking precautions like 'condomizing' or taking other precautionary measures before engaging in sexual intercourse. Expressions of anger were directed to either the spouse or partner.

#### **4.3.3.2 Revenge**

Some participants wanted to take revenge against others who they perceived to have infected them and to the HIV-negative individuals. They even stated that in order for anyone to be accepted as members of the support group, one needs to prove to the group that he or she is HIV-positive.

#### **4.3.3.3 Depression**

This was a common response from the participants after learning that they had been tested HIV-positive. Different responses were reported such as, not wanting to eat, sleeping a lot, crying a lot, not wanting to talk and having feeling of sadness and hopelessness. Some even contemplated committing suicide.

It is understandable to have such feelings and emotions when one is diagnosed as HIV-positive. However, it is also necessary to understand that there is life after one has been detected to be HIV-positive. The longevity of one's life would depend on the care and love that each and every individual gives and/or receives from friends and families.

It became evident during the emotional observations that in the realm of daily life, the most common forms of social isolation were the warning or disappearance of existing friendship and the reluctance of neighbours, relatives and friends to visit, lend or borrow common household implements and food items to HIV-positive individuals.

It also became evident during the interviews that so many emotions confront people after they have been diagnosed. As they face changing social support and financial situations, they can become frightened.

In view of the above-mentioned observations, the researcher then conducted three (3) therapeutic sessions consisting of ten members per session. The purpose of these sessions was to address concerns raised by members of the group. From the therapeutic sessions, it became necessary to make referrals for further counselling to the Departments of Welfare, Psychology and Empangeni Crisis Centre.

#### **4.4    Résumé**

The themes and quantitative data that emerged from the interviews have been presented, analysed and discussed. The above findings have important implications as they highlight the types and factors related to the process of disclosure among HIV-positive persons. The findings of this study also indicate that disclosure in HIV-infected clients is a complex decision and is often accompanied by perceived stigma, anticipated negative or positive behaviour from others, and the possibility of gaining access to care and support. However, the study is not without limitations. The next chapter points these out and makes recommendations for future research and concludes the study.

## **CHAPTER FIVE**

### **CONCLUSION AND RECOMMENDATIONS**

#### **5.1 Introduction**

This chapter concludes the present study on the basis of the data collected, the literature reviewed, and makes recommendations for future research. The limitations of the study and the implications thereof will be articulated.

#### **5.2 Summary of the main findings and their discussion**

Regarding revealing a conducive environment for disclosure; all participants (n=30) reported that the environment in the support group provide people with HIV a relaxed and informal place to share their experiences. According to the participants, support groups provide a non-judgemental environment where people with similar experiences vent their feels. They also reported that the environment in the support group is a major source of love and acceptance.

Disclosure of serostatus has implications for social support which in turn, may affect one's psychological well-being. The psychological impact of disclosing one's HIV-positive status has been shown to reduce the distress of having a chronic illness, including HIV/AIDS.

Past research has also revealed that disclosing an HIV-positive diagnosis to another individual may be an important contributor to one's perceived social support. The relationship between social support and disclosure may influence psychological adjustment (Moneyham & Seal, 1996).

All participants expressed a need to be empowered with different kinds of information. They also expressed the need for skills to deal with their issues, including their feelings about fear, changed social conditions, health concerns and obsessional thoughts.

Regarding the impact of disclosing one's HIV positive status it became evident that people living with HIV/AIDS are faced with an important dilemma regarding whether or not they should reveal their HIV-positive status to significant others. Disclosure is a painful experience. On the one hand, disclosure is expected to alleviate the stressful burden of concealment, to increase material and emotional support. On the other hand, disclosure exposes people living with HIV/AIDS to stigmatisation, discrimination and violence from significant others.

This finding is supported by research conducted by (Hays, 1993 and Chandra, 2003) who found that fear of AIDS-related stigma and concealment of one's serostatus causes delays in access to care.



The case of Gugu Dlamini also illustrated the discrimination and violence that could result from publicly disclosing one's HIV-status to others.

The results of the current study also indicated that among the 30 participants interviewed, seventy percent (70%) disclosed in order to elicit both financial and emotional support. Fifteen percent (15%) disclosed for financial support, and only ten percent (10%) felt that it was their responsibility to disclose as their partners needed testing.

This finding is supported by the social support theories who distinguished between three basis types of support that appear most important for people with chronic illnesses: informal, emotional and tangible. The results are also supported by Duffy (1994) who found that disclosing an HIV-positive status to another individual, is an important contributor to one's perceived social support. The interrelated relationship between social support and disclosure influences psychological adjustment.

Reasons given for non-disclosure include stigmatisation (100% of the participants); social isolation (70% of the participants); gossip (50% of the participants); rejection from the home (33% of the participants); rejection from the community (20% of the participants); verbal abuse (15% of the participants); rejection (40% of the participants) and (60%) reported fears related to society's attitudes towards the illness.

Hays, (1993) and Cole, (1996) indicated that hiding one's status may not only preclude HIV-related social support and its attendant benefits but may also have direct negative effects on disease progression for HIV-positive individuals.

With regard to the types of disclosure, table 4.1 revealed that sixty percent (60%) disclosure occurred voluntarily with the participant's consent, twenty-three percent (23%) disclosure occurred without the participant's consent and seventeen percent (17%) reported that disclosure had to occur as there was no any other choice.

Concerning the persons to whom disclosure occurred, participants gave multiple responses. Thirty-three percent (33%) reported to (parents, siblings and spouse); thirteen percent (13%) reported to (relatives such as in-laws, cousins, uncle). Twenty-three percent (23%) reported to support groups, seventeen percent (17%) reported to religious people only and thirteen percent (13%) reported to both neighbours and the community.

When the respondents were asked to list the aspects in which the environment in the support groups differs from that in the home and the community, **five** key themes emerged. They were:

- 1) "Talk about it in order to educate and prevent the spread..."
- 2) "Gaining support and coping with the illness..."

- 3) “Need to know and be empowered...”
- 4) “Places of healing...”
- 5) “Love and acceptance...”

All participants in this study agreed that HIV/AIDS education is necessary and there was no expressed opposition to HIV/AIDS education per se. The participants felt that parents should have sufficient information about HIV/AIDS to educate their children at home. The provision of information including abstinence from sexual intercourse, being faithful to one's partner and the use of condoms is very essential. Participants reported that this type of education is not provided at home but only received in the support groups.

This finding was supported by James and Glover (1993), who believed that parents, teachers and learners all need continuous education in the field of HIV/AIDS. Arguing in the same vein, is Selvan, Ross and Kapadia (2001) who found in their research that if parents are better educated and informed, adolescents are less likely to be sexually active.

The above findings have important implications as they highlight the types and factors related to the process of disclosure among HIV-positive persons.

The participants also indicated that gaining emotional and spiritual support for persons infected with HIV and their loved ones and care for partners, is a vital aspect of living with HIV.

All participants reported that in the support group environment they feel more responsible, useful, and empowered rather than to be frustrated by the community. They also reported that the environment in the support groups provides people with HIV a relaxed and informal place to share their experiences and build new friendships. Support groups are places of healing.

In support groups they gain acceptance, intimacy and acquire skills to deal with their issues, including their feelings about fear, changed social conditions, health concerns and obsessional thoughts. Support groups provide them with love and help them meet the challenges of social isolation, and enable them to cope with the various interpersonal stressors.

With regard to the research design, the study used participatory action research, which combined exploratory research and social action. The use of multiple methods is a plan of action that raises the psychologist, and other social researchers, above the personal biases that stem from a single methodology. By combining methods in the same study, researchers can partially, overcome the deficiencies that flow from one investigator or method (Denzin, 1989). It also minimises the major

threats to reliability and validity and increases confidence in results and conclusions of the study.

On the other hand, with participatory action research, empowerment is a key to all other issues. Participation in knowledge creation that is generated knowledge created by PAR set the groundwork for empowerment. Empowering the participants also implies improving their capacity to solve problems and achieve their objectives. Thus, empowerment is a key to all other issues in PAR. Learning in PAR is at empowering participants. In PAR, learning is considered to be ongoing or continual, and therefore, inseparable from PAR's research functions.

#### **5.2.1 Summary of the results from the focus groups**

From the in-depth interviews with the focus groups, the following themes emerged as accounts of emotional observations and were summarized as follows:

- **Isolation:** Focus group members reported that being diagnosed as HIV-positive is extremely isolating. They also expressed the feelings that being diagnosed as HIV-positive lead to the abandonment by friends and family members. In some instances, co-workers may not even want to work or eat with them. Participants indicated that they feel sad, tearful, angry and anxious. Sometimes, as they explained,

“We lose hope in the future.” These feelings sometimes become so strong that one cannot carry on with day-to-day activities.

On the other hand, some were saying: ‘Knowing that they have a fatal illness, gives them courage to focus on what is important for them.’

- **Social stigma:** Focus group members expressed the views that people with HIV and AIDS are highly stigmatised and blamed for becoming infected with the virus because of their irresponsible behaviour, and for bringing shame to them, their families, communities, and being a burden to both their families and communities.

The researcher also observed the expressions of verbal stigma which were expressed through insulting, mocking, cursing and threatening to those living with HIV/AIDS. Expressions of verbal stigma also included blame, and shame often through judgemental statements indicating the HIV/AIDS infected people deserve what they have since they got what they wanted.

Other emotional observations were anger, revenge and depression.

- **Anger:** Some participants were angry at themselves and others by not taking precautionary measures before engaging in sexual intercourse.

- **Revenge:** Some participants wanted to take revenge against those who they perceived to have infected them.
- **Depression:** Depression was a common response from all participants after learning that they had been tested HIV-positive. Different responses were reported such as, not wanting to eat, sleeping a lot, crying a lot, sadness and hopelessness.

In view of the above-mentioned observations with the focus groups, the researcher then conducted three (3) therapeutic sessions consisting of ten members per session. From the therapeutic sessions, it became necessary to make referrals for further counselling.

With regard to empowerment, community psychology played an important role in shaping this study because of its action focus on groups. This study has demonstrated a need to develop an intervention programme that will address the most common barriers to disclosure such as, fear of rejection and discrimination, AIDS related stigma, denial, anger and fear of violence. It is hoped that such a programme will result in a downward trend in the epidemic and our best hope for a brighter future. Also, transforming AIDS into a treatable or controllable chronic condition has the potential to change community perceptions of people living with AIDS.

This intervention programme will also include massive awareness and sensitisation for preventing the spread of HIV/AIDS particularly targeting school boys and girls.

### **5.3 Limitations of the study**

The sample for the present study consisted of participants from one support group and excluded participants from other support groups around KZN. Therefore, the findings cannot be generalized beyond the specific sample studied.

As indicated in Chapter three of the present study, the limitations of PAR are:

- Variables are difficult to control
- The close relationship between the “researcher” and “participant” makes it difficult for the “researcher” to be objective and the research is, therefore, vulnerable to all kinds of bias.
- The necessary narrow focus of research (to a particular community with a particular difficulty) prevents the researcher from generalizing findings to other communities (Bless, Smith, Kagee, 2006).



## **5.4 Recommendations**

- Government needs to invest more money in HIV/AIDS research and training programmes for HIV/AIDS counsellors, medical doctors, traditional healers and communities at large.
- More research needs to be done in order to give support to people who are HIV-negative to address and alleviate their fears which may be interpreted as discrimination.

## **5.5 Conclusion**

Disclosure of one's HIV-positive status is an important public health goal for a number of reasons. Firstly, disclosure may motivate sexual partners to seek testing, change behaviour, and decrease the levels of community discrimination and stigmatization as well as the eradication of myths about HIV/AIDS.

In addition, disclosure has a number of potential benefits for HIV-positive individuals including increased opportunity for social support, improved access to medical care including anti-retroviral treatment, increased opportunities to discuss and implement HIV risk reduction with partners and increased opportunities to plan for the future. The interrelated relationship between social support and disclosure may also influence psychological adjustment.

Educational programmes aimed at sensitisation, reduction of the vulnerability to HIV/AIDS, and the prevention of the spread of HIV/AIDS are essential to all communities around South Africa.

The government's decision to provide anti-retroviral treatment creates the opportunity to rebuild bridges and to make one more attempt at turning the tide of HIV/AIDS.

Governments, the private sector, civil society, the business sector, the military, and those affected and infected by HIV/AIDS both in and outside Africa must form partnerships without delay to fight against the HIV/AIDS pandemic. This is no small task, but it can be achieved, indeed it has been achieved in several countries.

The researcher can conclude by saying that the present study has made valuable contribution to our understanding of the issues of disclosure, and the introduction of an intervention programme to address the common barriers associated with HIV/AIDS disclosure despite a few limitations. The reader's attention is drawn to the attached proposed programme of intervention which was the ultimate aim of the present study (ANNEXURE A).

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## **ANNEXURE A**

### **PROPOSED INTERVENTION PROGRAMME**

#### **Introduction**

HIV and AIDS present a unique challenge to society. No disease of recent times has produced more ethical dilemmas, been responsible for such destruction of family life or placed greater demands on health education and social services than has this viral affliction and its complications.

Several studies have confirmed that existing HIV/AIDS education programmes in South Africa have had limited impact on sexual behaviour. Surveys show that about 98 percent of South Africans are aware of HIV/AIDS and how it spreads, but condom use among South African males has remained almost unchanged at about 10 percent over the past five years. AIDS is currently out of control, one in three women in South Africa gives birth before the age of 18, sexually transmitted infections are endemic among young people in large parts of South Africa. Thus, in line with the aims of the present study, the proposed programme seeks to:

- Reveal to the public a conducive and non-threatening environment for disclosure
- Empower HIV-positive individuals to seek appropriate support and counselling

- To establish the importance and the assessment of the psychological impact of disclosing one's HIV-positive status.

The proposed programme will comprise of **two** modules organized as follows:

**MODULE ONE:** The module shall be called:

CANTED: Conducive and non-threatening environment for disclosure

**MODULE FORMAT AND CONTENT:**

The module shall consist of workshops with HIV-positive individuals lasting for **three days.**

## DETAILS: DAY ONE SESSION

**Student orientation and introduction:**

i.e. Module outcomes and workshop structure

TIME: : MODULE PRESENTER

## Perceptions and precautions regarding HIV and AIDS

TIME: : MODULE PRESENTER

### Questions and answers from the participants

Myths and realities about HIV/AIDS

TIME: : MODULE PRESENTER

Questions and answers from the participants

## DAY TWO SESSION

(i) RECAP: 30 Minutes

(ii) Living positively with HIV/AIDS

TIME: : MODULE PRESENTER

Questions and answers from the participants

HIV-positive speaker discusses his/her experiences of being HIV- positive

TIME: : VOLUNTEERING SPEAKER

Discussion of speakers experiences

TIME: : MODULE PRESENTER

Questions and answers from the participants

Cases of Judge Cameron and Gugu Dhlamini are made as references and open

for discussion

### **DAY THREE SESSION:**

- (i) Recap: 30 minutes
- (ii) The importance of disclosure to a sexual partner, children or significant other

TIME: : MODULE PRESENTER

Questions and answers from the participants

Addressing the needs of those not ready to disclose

TIME: : MODULE PRESENTER

Questions and answers from the participants

Discussion of community and family education

TIME: : MODULE PRESENTER

Questions and answers from the participants



Evaluation of the module by a test or feedback questionnaire by the participants
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### **Module One: Summary**

It is hoped that this module will provide the participants with an opportunity within a non-threatening environment to learn facts about the importance of disclosure, and to examine their own attitudes in this regard.

The sharing of one's HIV-positive experiences with others will help to inspire openness and encourage the participants that despite being infected, one can still live a healthy life style for years.

The session on "myths and realities about HIV/AIDS" it is hoped that this discussion will encourage the participants to freely ask questions and explore aspects of HIV/AIDS which they need to deal with from a personal perspective.

This session will also help to clarify frequently asked questions about HIV/AIDS, sexuality, gender and sexual decision making.

With regard to the community education component, HIV/AIDS awareness/presentation for communities is essential. The most valuable aspect of this outreach component would be to visit schools and make presentations in order to provide information on HIV/AIDS.

Sexual partners of HIV-positive people are at increased risk of becoming HIV-positive. For these partners, knowing their HIV-status is very important. Thus partners need to know how they can help reduce the risk of infecting one another. Therefore, guidance on HIV-status disclosure on reducing the risk of infecting others is essential in counselling for “living positively.”

In addressing the needs of those not ready to disclose, the process of networking and sharing experiences has served as powerful therapy for individuals, families and communities.

**MODULE TWO:** The module shall be called:

EHPAS C: Empowering HIV-positive individuals to seek appropriate support and counselling
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**MODULE FORMAT AND CONTENT:**

The module shall consist of workshops with HIV-positive individuals lasting for **two days.**

**DETAILS: DAY ONE SESSION:**

Student orientation and introduction i.e. module outcomes and workshop structure

TIME: : MODULE PRESENTER

Barriers to HIV/AIDS disclosure:

- (i) Stigmatization and Discrimination

TIME: : MODULE PRESENTER

Discussion: Questions and Answers

Barriers to HIV/AIDS Disclosure:

- (i) Anger and Denial

TIME: : MODULE PRESENTER

Discussion: Questions and Answers

## **DAY TWO SESSION:**

Recap: 30 minutes

Barriers to HIV/AIDS Disclosure:

(i) Depression and Fear

TIME: : MODULE PRESENTER

Discussion: Questions and Answers

Positive outcomes of disclosure

TIME: : MODULE PRESENTER

Discussion: Questions and Answers

Psychological and social support for people living with HIV/AIDS:

Using Role Plays

Discussion: Questions and Answers

Preparing for goodbye

(i) Life skills and capacity building

(ii) Evaluation of the module by a test or Evaluation Questionnaire
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Closing Ceremony and issuing of Attendance Certificates
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## **Module Two : Summary**

It is hoped that the module will bring to light the importance of support to people living with HIV/ADS, and also assist to address and deal with the common barriers to disclosure. People living with HIV/AIDS often suffer in silence because of their fear of discrimination and stigmatization. Silence can contribute to the development of depression and reduce the likelihood of one's seeking information and treatment. The module will also acknowledge that anyone can harbour conscious or sub-conscious stigmatising thoughts or attitudes, but will emphasize that anyone can also address and deal with stigma in small or large ways.

The session on anger and denial. In regard to anger which may include blaming the person suspected of infecting you, yourself or even blaming God, this may be a difficult session to deal with. It is, therefore, important for the module provider to advice the person suffering from HIV/AIDS not to take it personally, but to help the person to talk about their feelings. Denial which may be a subconscious way to protect oneself from the pain associated with the threats posed by HIV/AIDS, it is important for the module provider to make the HIV-positive individual to understand the HIV test and its results.

On the issue of depression and fear. Depression can make someone very weak in body and mind. This is a common response to learning that one is HIV-positive. It may be necessary to refer the person to a doctor or counselling. People who have been tested HIV-positive may fear death, abandonment, violence, upsetting family members and other things. By joining a support group may help to work through these fears. It is important for a person with a positive result to move into places of healing and hope.

Caring and supporting people living with and affected by HIV/AIDS puts a large percentage of them on the road to recovery. By using role-plays and other behavioural rehearsal techniques, HIV counselling can be used to develop interpersonal communication skills among clients for HIV status disclosure. The module presenter can strengthen communication skills and increase perceived self-efficiency for disclosure through the use of role-plays, scenarios and other behavioural rehearsal techniques. The techniques not only help HIV-positive individuals identify the communication challenges that they may face when disclosing to their sexual partners, but also serve as an opportunity to develop a personal disclosure plan with the module presenter.

Social support theories distinguished between three basic types of support that appear most important for people with chronic illnesses: Informal, emotional and tangible. Informal support helps people stay grounded in the realities of their condition. Emotional support is offered through affection and empathy. Both informal and emotional support have been shown to reduce the distress of having a chronic illness, including HIV/AIDS. Tangible support is also important for people with HIV/AIDS, particularly at the later stages of the disease, when they need help with meals, housekeeping, shopping, transport and other tasks of daily life. The interrelated

relationship between social support and disclosure influences psychological adjustment. Also, research has also shown that HIV-positive individuals who share their status with a family member or their partners demonstrate significant lower levels of emotional distress than those who chose to keep their status secrete.

Life skills and capacity building are important to assist HIV-positive individuals for personal development, confidence, social competence, self-esteem and the ability to act with respect and responsibility.

## **ANNEXURE B**

### **A. QUESTIONNAIRE: BIOGRAPHICAL INVENTORY**

1. Identification Number: .....
2. Age: ..... Years ..... Months
3. Your level of Education: .....  
.....
4. Your Marital Status:

Single	
Married	
Divorced	

5. Employment Status:

Employed	
Unemployed	
Self Employed	

### **B. INDIVIDUAL ASSESSMENT QUESTIONNAIRE**

1. How would you define HIV/AIDS now?  
.....  
.....  
.....
2. How did you define HIV/AIDS before?  
.....  
.....  
.....



3. What were the reasons for testing your HIV status?

.....

.....

.....

4. After testing for your HIV status, were you found to be?

Having HIV-related symptoms	
Diagnosed to be asymptomatic	
Your partner had HIV-infection	

5. Do you think that having heterosexual unprotected contacts can?

Increase the chances of acquiring the infection	
Does not increase the chances of acquiring the infection	

6. When you were diagnosed to be HIV positive, did you choose to disclose your status to your immediate family member such as:

Parent(s)	
Sibling(s)	

OR

To both immediate and extended family members such as:

Your in-law(s)	
Your cousin(s)	
Your Uncle(s)	

OR

Disclose to:

Professionals only	
Religious people only	
To a neighbour(s)	
Community (publicly)	
Support group(s)	

7. What were the reasons for disclosing your HIV positive status?

.....

.....

.....

8. What were the reasons for not disclosing your HIV positive status?

.....

.....

.....

## **ANNEXURE C**

### **CONSENT FORM**

**Consent to voluntarily participate as a research respondent in the present study.**

**1. Description of the research project:**

**Objectives of the project:**

- To reveal to the public a conducive environment for disclosure
- To establish the importance and the assessment of the psychological impact of disclosing one's HIV- positive status
- To empower HIV-positive individuals to seek appropriate support and counseling

**2. Methods and Instruments to be used:**

- Individual Questionnaires
- Focus Groups Interviews

**3. I consent to voluntarily participate in the present study as a member of the support group under the following conditions:**

- That I shall remain anonymous as a research participant, and my anonymity is guaranteed.
- That the present research undertakes to respect my privacy and dignity.

**Thus signed..... at..... on.....day.....**