

A PHENOMENOLOGICAL INVESTIGATION  
INTO THE LIVES OF HIV POSITIVE  
SOUTH AFRICANS

2003

SHELLEY KIM HALL

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A PHENOMENOLOGICAL INVESTIGATION INTO THE  
LIVES OF HIV POSITIVE SOUTH AFRICANS

BY

SHELLEY KIM HALL

IN PARTIAL FULFILLMENT OF THE REQUIRMENTS OF A  
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SUPERVISOR: DR HSB NGCOBO

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## **ABSTRACT:**

Many myths and stigmas around HIV/AIDS continue to exist, despite various campaigns to educate South Africans about this terminal illness, and therefore an HIV positive diagnosis and the experience of living with it are usually kept secret. In order to facilitate a better understanding of HIV positive South Africans, it seems necessary to research their experiences. This study, using the phenomenological methodology, examined 6 HIV positive participants' written stories about their experiences of living with HIV. From these stories the following main themes emerged: disclosure, denial, stigma, physical symptoms, symbolic representations of HIV/AIDS, medication, depression, anger, and death, and from these themes strategies for survival materialized. The findings of this study show that HIV is often minimized by the infected so that they are able to manage the experience in more publicly acceptable ways, such as by focusing on common physical illnesses, and avoid facing the "emotional baggage" that accompanies this virus. The findings of this study reveal a need for further research in this experiential area as well as campaigns and education around issues such as stigma, medication, and emotional difficulties.

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## **CONTENTS:**

<b>CHAPTER 1 – INTRODUCTION</b>	<b>1</b>
1. Introduction	
2. Statement of the problem	2
3. Research methodology and data analysis	
4. Value of the study	3
5. Motivation for the study	4
6. Aims	5
<b>CHAPTER 2 – LITERATURE REVIEW</b>	<b>5</b>
1. Introduction	
2. The basics of HIV	
2.1. A brief history of HIV	
2.2 What does HIV positive mean and what symptoms are experienced?	6
2.3 When does HIV become AIDS?	7
2.4 How is the virus transmitted?	
3. Learning you are HIV positive	8
3.1 Reactions to diagnosis	
3.1.1 Women's reactions to a positive diagnosis	9
3.1.2 Children's reactions to a positive diagnosis	
3.2 Coping after initial reactions	10
3.3 Disclosure	
3.3.1 Double disclosure	11
3.3.2 Disclosure in communities	
3.3.3 Disclosure among gay and bisexual men	
3.3.4 Disclosure in the workplace	12
3.3.5 Disclosure to children	13
3.3.6 Disclosure to family	14

3.3.7 Public disclosure	
3.3.8 Men's reactions to female partner's disclosure	15
4. Psychosocial Issues	
4.1 Stigma and Discrimination	
4.1.1 What is stigma and discrimination?	
4.1.2 After so many years of knowledge of the virus why is there still so much stigma?	16
4.2 Support	17
4.2.1 Social Support	
4.2.2 Family Support	
4.3 Workplace	18
4.4 Specific issues for:	20
4.4.1 Women	
4.4.2 Men	
4.4.3 Children	21
4.4.4 Adolescents	
4.4.5 Drug Users	22
4.4.6 Homosexual and bisexual People	
4.5 Sex	
5. HIV and Psychiatric Disorders	23
5.1 Depression	
5.2 Anxiety	24
5.3 Insomnia	25
5.4 Bereavement	
6. Antiretrovirals	

7. Income and Productivity	26
8. Conclusion	
<b>CHAPTER 3 – METHODOLOGY</b>	<b>27</b>
1. Introduction	
2. Methodological orientation	
3. Participants	29
4. Design and data collection	30
5. Analysis and interpretation	
6. Discourse analysis	33
<b>CHAPTER 4 – RESULTS</b>	<b>35</b>
1. Introduction	
2. Themes	
3. Main themes	36
3.1 Disclosure	
3.2 Stigma	41
3.3 Denial	42
3.4 Physical Symptoms	44
3.5 Symbolic representations of HIV/AIDS	46
3.6 Medication	47
3.7 Depression	49
3.8 Anger	51
3.9 Death	52
4. Summary	53
<b>CHAPTER 5 – DISCUSSION</b>	<b>54</b>
1. Introduction	
2. Discussion of main themes	
2.1 Disclosure	
2.2. Stigma	56

2.3. Denial	57
2.4. Physical symptoms	58
2.5. Symbolic representations of HIV/AIDS	59
2.6. Medication	59
2.7. Depression	60
2.8. Anger	63
2.9. Death	
3. Summary of the discussion	64
4. Implications	65
5. Limitations of this study	66
6. Conclusion	
REFERENCES	67
APPENDICE A	76
B	86

## CHAPTER 1

### 1. Introduction

Although HIV, human immunodeficiency virus, has been around since the 1980s, its transmission scientifically discovered, and various campaigns to educate people about HIV/AIDS, Acquired Immune deficiency Syndrome, given, many myths and stigmas continue to exist. As a result of this continued stigma and discrimination, an HIV positive diagnosis and the experience of living with it is usually kept secret in South Africa. HIV is a unique, life threatening illness as there is no cure and it is associated with behaviors of which society does not approve (Hodgson, 1999) and thus society and families often reject people living with the virus, while some experience compassion and support. Sinkoyi (2000) describes HIV as a diagnosis that is unique from other life-threatening conditions because it influences not only the individual, but also the uncertainty found socially, psychologically, medically, and in terms of prognosis.

Many HIV positive people hide their status from family, employers, and friends due to the fear of rejection (Kinniburg, Scott, Gottlieb, & Power, 2001; Sinkoyi, 2000) and are forced to carry the burden silently. Thus HIV positive people do not always receive the social support that research has shown to be of great value and this may lead to a life of isolation, depression, and loneliness (Duyan, Agalar, & Sayek, 2001; Serovich, 2001; Leask, Elford, Bor, Miller, & Johnson, 1997).

In addition to the burden of living with a life threatening illness, many HIV positive South Africans have to face daily hardships, such as poverty, gender inequalities, unemployment, lack of health services, and housing, thus diversifying the HIV experience even more (UNAIDS, 2002). Changes, such as weight loss and CD4 count, as well as decisions, such as disclosure and lifestyle, shape each individual's experience and often bring new to fears and anxieties (Moore, Rosenthal, & Mitchell, 1996).

Sinkoyi (2000) found that people living with HIV often perceived stigmas to exist, but upon revealing their status found that these stigmas did not always exist. It seems important, therefore, that individuals are able to move beyond stigma and find ways of revealing and living with their HIV positive status if they are to have positive life experiences.

It seems that if we are to fight stigma and discrimination, we need to eradicate fear and misunderstanding. Perhaps one way of doing this is to allow HIV positive South Africans to express themselves by sharing their stories of their experiences of living with HIV. Hopefully by doing so other HIV positive South Africans may realize they are not alone and find the courage to disclose their status. For HIV negative South Africans, perhaps reading stories of fellow citizens will provide insight and understanding, thus removing some of the mystery and fear.

## **2. Statement of the problem**

An HIV positive status is associated with a number of problems for both the infected and uninfected. In order to address issues of stigma, discrimination, and fear it is necessary to study the experiences of HIV positive people. If these issues are not addressed HIV positive people will continue to live with an extra burden. Stigma and fear contributes to denial, which in turn may contribute to the spread of HIV. Therefore, in order to improve the lives of HIV positive people and to target the stigmas of the illness, it is necessary to investigate their lives.

## **3. Research methodology and data analysis**

This study provides an opportunity for HIV positive South African to express themselves and for the rest of the population to gain insight into what it is like to be HIV positive. This study is a qualitative investigation into HIV positive South

African's experiences. Following the Phenomenological Philosophy, this study endeavored to gain an understanding of HIV positive individuals' perspectives and views of what it is like to live with HIV (Leedy, 1997). Written stories from 6 participants about their experiences of living with HIV were used to obtain a general picture of what it is like to be HIV positive.

Purposeful sampling was applied to choose suitable participants. This sampling method allowed for the selection of knowledgeable and informative subjects.

Terre Blanche and Kelly's (1999) guidelines for interpretative data were used to analyze and interpret themes from the 6 participants' stories. Chapter 3 will provide an in-depth discussion of these steps. Chapter 4 will reveal the results of this analysis and chapter 5 provide a discussion of these results in the light of existing literature.

#### **4. Value of the study**

The value of this study extends to many areas. Firstly, it attempts to provide insight into HIV positive South African's lives. This insight gives some idea of South African's attitudes towards HIV, and thereby reveals what areas need targeting in order to improve these attitudes. Thus this study should also provide some idea of how effective campaigns that attempt to reduce stigma and discrimination are. This study identifies some of the needs of HIV positive South Africans and provides ideas for improving services. Thus this study may help improve the quality of HIV positive people's lives. In addition little research has been conducted in this area of HIV, thus new ideas may be generated for future research and new findings shared.

## **5. Motivation for the study**

My idea for this topic came from my honors' research project and my supervisor, Dr. H.S.B Ngcobo. My honors' research project, 'Attitudes of young adults towards HIV/AIDS' (Hall, 2001) provided a one sided view of the HIV/AIDS story. I wanted to know more of what it was like to live with HIV and where HIV/AIDS campaigns were failing. My supervisor helped me devise a topic that would answer my curiosities.

## **6. Aims**

The aims of this study are to gain insight and understanding of what it is like to be HIV positive, so that suggestions can be made for counseling and future HIV/AIDS awareness campaigns. In addition, findings will hopefully help to create understanding and thus reduce stigma, as well as identify some of the needs of HIV positive South Africans.

## **CHAPTER 2: LITERATURE REVIEW**

### **1. Introduction**

This chapter will review literature relating to HIV/AIDS. The review will begin with a brief look at the history of HIV/AIDS, what it means to be HIV positive, and how the virus is transmitted. This will be followed by literature focusing on reactions to diagnosis, disclosure, and psychosocial aspects of HIV, such as stigma and social support. Lastly, literature on psychiatric illness related to HIV, antiretrovirals, and income and productivity will be discussed. It is hoped that this chapter will introduce the reader to some of the issues facing HIV positive people.

### **2. The basics of HIV**

#### **2.1 A brief history of HIV**

HIV, a virus of the retrovirus family, causes AIDS. There are two types of HIV, one and two. HIV-1 is found all over the world and HIV-2 is mainly found in West Africa. HIV-1 is just as dangerous as HIV-2, but HIV-2 takes longer for symptoms of infection to develop (Fan, Connor, & Villarrea, 1989; Green & McCreamer, 1992; Moore et al., 1996).

The origins of HIV are unknown. It is thought that some time during the twentieth century HIV spread from primates to humans, perhaps through a bite or open lesions. Although there is some evidence of HIV in the 1940s, the first recognized case of AIDS occurred in America, 1981 (Moore et al, 1996). The first two AIDS cases in South Africa were diagnosed in 1982 and the first death was recorded in 1985 (Shell, Quattek, Schonteich, & Mills, 2000). A simultaneous outbreak of both *Pneumocystis carinii* and Kaposi's sarcoma were found in several patients

who were mainly young homosexual men. In central Africa a disease that undermined the immune system was also discovered. Only in 1983 was it found that a virus, which was then named Lymphadenopathy associated virus (LAV) by the French, and human T-cell lymphotropic virus Type III (HTLV-III) by the Americans, caused these diseases. Later, in May 1986, the virus was renamed Human Immunodeficiency Virus (HIV) (Van Dyk, 2001).

## **2.2 What does HIV positive mean and what symptoms are experienced?**

To be HIV positive means that a sero-conversion has taken place. This occurs 4 to 8 weeks after the person has become infected with HIV. The person now changes from an HIV negative or uninfected state to an HIV-positive or infected state (Van Dyk, 2001). The presence of the virus is recognized through the body's response to it. The body tries to fight the virus by producing antibodies, which look different from those created in response to other viruses. Tests, such as ELISA and western blot, are used to detect the presence of HIV infection.

During sero-conversion some people may experience a variety of symptoms, while others remain asymptomatic. When the antibodies first appear in the blood some people may experience 'seroconversion illness' which is similar to glandular fever. Others may have persistently swollen lymph glands known as persistent generalized lymphadenopathy (PGL). Fever, severe unexplained fatigue, and headaches may also be experienced. Some people may remain for years in the asymptomatic phase or the PGL phase, but others may progress. Those that progress are described as having AIDS-related complex (ARC). These people do not develop diseases diagnostic of AIDS, but have other symptoms that show their bodies are not fighting the infection. Symptoms include fevers, 'night sweats', weight loss, diarrhea, shingles, and a lack of energy (Fan, et al., 1989; Green & McCreamer, 1992; University of Pittsburgh Medical Center, 2003).

### **2.3 When does HIV become AIDS?**

Progression of HIV eventually causes the immune system to deteriorate so that it can no longer fight the virus and more untreatable opportunistic conditions appear. Aids is diagnosed once the person has one of three criteria: opportunistic infections, such as tuberculosis and thrush, opportunistic tumors, such as Kaposi's sarcoma, or AIDS related encephalopathy (Fan et al., 1989; Green & McCreamer, 1992; Moore et al, 1996).

### **2.4 How is the virus transmitted?**

Infection results when the virus enters the person's blood stream and there are a number of ways in which this happens.

Sexual intercourse is one way of transmission of HIV. It may be transmitted through unprotected sexual contact, including oral and anal sex. During sex the virus may be absorbed into the body fluids or into torn membrane linings of body cavities (Van Dyk, 2001). Semen, vaginal, and cervical secretions can contain the virus and thus transmit it if it gets into another person's body.

Exposure to contaminated blood, such as through intravenous drug use or an accidental prick from a needle used to treat an infected person, are also ways of transmission. Some people have been infected via blood transfusions, but testing of the donated blood before use has reduced the number of cases (Van Dyk, 2001).

Breast milk contains HIV and there is evidence that babies have been infected after birth through breast-feeding. Intra-uterine infection may also occur (Moore et al., 1996).

The risk of transmission is related to two factors: firstly, the amount of virus present in the body fluid or tissue and secondly, the fact that the virus must enter the body in order to cause infection. The higher the concentration of the virus in the body, the higher the risk of transmission. For infection to occur the virus must come into contact with non-skin surfaces or be carried through the skin (Fan, et al., 1989; Green & McCreamer, 1992).

### **3. Learning you are HIV positive**

#### **3.1 Reactions to diagnosis**

Receiving a positive test result for HIV is a unique experience for each individual, however a few common reactions and emotions have been identified. Shock followed by denial, fear, anger, guilt, and or shame are usually the first reactions experienced (Moore et al., 1996; Paxton, 2001; Coleman, 2003). Andrews & Novick (1995) also name some common reactions: denial, self-blame, fear, anxiety, anger, control, isolation, loss, ambivalence, empowerment, spirituality, and hope.

Coleman (2003:1) states that 'people frequently report their experience of receiving an HIV positive diagnosis as similar to going into shock'. He explains further by describing that people often do not remember anything a few hours after the diagnosis, even though they may appear to be functioning normally. Feelings such as fear and emotional numbing may also be experienced. Fears of having infected past partners or fears of future transmissions may lead to feelings of guilt and shame. Moore et al. (1996) describe similar findings in studies done by Ross et al (1989) and Grant and Anns (1988). Reactions of calmness, indifferent denial, or insistence on mistaken diagnosis were rare, with anger being the most common reaction. Grant and Anns (1988, as cited in Moore et al., 1996), interpret this anger as a positive reaction to an HIV positive diagnosis. These studies also found depression to be a common reaction. Many

of their clients showed reactive depression expressed as apathy, little interest in future goals, a lack of energy and interest in life. Some simply withdrew from social interactions. Ross et al (1989, cited in Moore et al., 1996), found that for some gay men part of this withdrawal meant a return to the closet.

### 3.1.1 Women's reactions to a positive diagnosis

Neuvians' (1988) study of Kenyan women's reaction to a positive diagnosis revealed that most women reacted with denial. They expressed denial in different forms. Some blamed their symptoms on things other than their HIV status, such as sorcery, while others simply refused to believe it for a variety of reasons, such as they did not look like their preconceived idea of how an HIV positive person looked. Other women became angry and blamed their partner for their infection. Worry or fatalism was the reaction of others; they expressed concern about their children or comforted themselves in the thought that everyone is dying anyway. Another common response was that of self-blame or guilt or shame. For example, some blamed themselves for the infection or they tried to hide their shame by blaming other sources of infection, such as a tooth extraction (Neuvians, 1988).

### 3.1.2 Children's reactions to a positive diagnosis

Children's reactions to their parents' status and their own is often not what parents expect. The Francois Xavier Baynoud (FXB) center (1997), of the University of Medicine and Dentistry of New Jersey, found that children often use denial to cope with this news. Another common response identified by the center is that of sadness and depression, which often lasts for days or weeks. It has been found that children are resilient and learn to live with HIV if they are given support. It seems that support groups are best in helping HIV positive children deal with the diagnosis. Chirila, Petrea, Cotoanta, and Voicu (2002) reported similar findings.

It cannot be predicted how a person is going to react to an HIV positive diagnosis, however it seems that a few common responses can be expected across gender and age.

### **3.2 Coping after initial reactions**

According to Grant and Anns (1988, as cited in Moore et al., 1996), after the initial reactions have been worked through HIV positive people begin to seek information and counseling. Many questions about death and spirituality are raised and people may seek to resolve conflicts and deal with unfinished business. Some decide to take steps to live positively, some remain angry and follow a self-destructive path, and others begin to disengage from life. Grant and Anns (1988, as cited in Moore et al., 1996) thus place coping styles into three categories: those who seek to improve the quality of their lives through adaptive means, those who become neurotic or obsessive about their life and lead a symptom oriented lifestyle, and lastly, those who cannot cope and simply withdraw, often becoming depressed and suicidal. These coping styles are not necessarily stable; they may fluctuate depending on preexisting coping mechanisms, support, and stage of the virus (Moore et al., 1996).

### **3.3 Disclosure**

Any person diagnosed with HIV has to decide whether or not they should tell their family, friends, and employees. Due to the stigma and discrimination associated with HIV, the dilemma of deciding who to tell and how to tell is very difficult for an HIV positive person, as it is often impossible to judge how people are going to react. According to numerous studies, not being able to disclose one's illness appears to have many negative effects on one's life (Serovich, 2001; Sinkoyi, 2000; Travers & Paoletti, 1999; Key et al., 1998; Leask et al., 1997; Herek, 1990; Herek & Glunt, 1988). Levy, Laska, Abelhauser, Delfraissy, Goujard, Boue, & Dormont (1999) state that disclosure is a reflection of how a

person is experiencing and coping with HIV. Thus those that do not disclose are unable to adapt to their illness and may self-impose exclusion from society. Further, their study found that disclosure is a compulsive act to release tension, rather than trusting someone or fulfilling obligations of societal responsibility.

### 3.3.1 Double disclosure

Disclosure of HIV may make it necessary to disclose other behaviours, such as informing someone that one is bisexual or gay, having extramarital relationships, or using drugs (Coleman, 2003). This may make disclosure even more emotional and difficult.

### 3.3.2 Disclosure in communities

HIV positive people living in smaller communities often have a greater challenge, especially if they decide to keep their status secret, since other opportunities for support may be less available than in bigger communities. It has been found that those who do disclose in smaller communities often find themselves in the position of educating the community. This has had both rewarding and disastrous effects. Disclosing in a community may become more complicated, especially if the person is part of a community that is already discriminated against. This leaves the HIV positive person with even fewer places to go for support and health care (de Bruyn, 1998).

### 3.3.3 Disclosure among gay and bisexual men

Disclosure has been found to play an important role in coping with HIV infection in both gay and bisexual men. It seems that disclosure is a coping mechanism. It is also used to increase support, share responsibility for sex, and help with self-acceptance. Thus, it appears that disclosure for gay and bisexual men helps to

reduce stress and contend with their HIV positive status (Holt, Court, Vedhara, Nott, Holmes, & Snow, 1998).

### 3.3.4 Disclosure in the workplace

Individuals in the workplace need to disclose their HIV positive status for a variety of reasons. They may need to be accommodated in terms of time-off for appointments and a lightened workload. Antiretroviral drugs and their side effects have brought a new danger into the workplace (de Bruyn, 1998). For example antiretrovirals may cause drowsiness, which is hazardous for those operating machinery or for those required to drive. Dosage schedules and meal times may require special accommodations and side effects may prevent the person from performing certain duties. Fesko (a: 2001) noted individuals left rather than disclosing their status due to fear of being stigmatized and discriminated against. By not disclosing HIV positive people are often forced to continue with duties that are too stressful for their immune systems, thereby endangering their health, or they are forced to quit their jobs because they are unable to ask for lighter duties. Often those returning to work prefer to seek employment elsewhere. However, *this is frequently not always possible, as they may have lost skills or require training* (de Bruyn, 1998).

Disclosure at work has led to more positive consequences than expected (Simoni, Mason, & Marks, 2002; Fesko, b: 2001). However, unpleasant and negative experiences, such as being shunned at work or being the subject of gossip, are common too (Fesko, a: 2001). Fesko (a: 2001: 237) describes the disclosure of HIV status as a 'double-edged sword', since it both creates opportunities for medical and social support, but also creates stress because of stigma, discrimination, and disruption of relationships. In her study she found that people chose not to disclose because of privacy, the nature of the work environment and fear of potential consequences. However, those who did

disclose felt more relaxed and generally more positive from the reactions of others (Fesko, 2000).

Vest, Vest, and O'Brien (1995) found that disclosure in the work place is determined by legal concerns, fear of AIDS, and gender. Their study found that male managers were more likely to disclose to co-workers rather than other female managers. Fesko (2000) reported that women were less likely than men to fully disclose their health status in their workplace.

### 3.3.5 Disclosure to children

HIV positive parents often fear disclosing their status and their child's status to their child in anticipation of a variety of negative reactions. They often believe they are protecting their child by not disclosing. Many parents are uncertain as to how to disclose to their children (Chirila et al., 2002; Schrimshaw & Siegel, 2002; FXB center, 1997). Parents often fear that their child will reject them or will consider suicide (Schrimshaw & Siegel, 2002; FXB center, 1997). The FXB center (1997) found that children rarely want to commit suicide and never reject their parents, although they may express anger. Difficulties in adjustment to disclosure, for a group of children living in an inner city environment where poverty and crime are high, were expressed in 4 areas of psychosocial adjustment: externalizing problems, such as aggression, internalizing problems, such as depression, pro-social competence, such as peer relationships, and cognitive competence, such as academic performance. Some studies suggest that a child's adjustment to disclosure depends on the child-parent relationship and the home environment (Forehand, Armistead, Mose, Simon, & Clark, 2003). Positive experiences such as improved attitudes towards clinical processes and compliance with antiretroviral treatment are found when disclosing to children. Families, after disclosure, experience positive changes, such as a decrease or total disappearance of tensions caused by secrecy and other negative emotions.

Thus a return to some form of normality may be experienced after disclosure to children within the family (Chirila et al., 2002).

Schrimshaw and Siegel (2002) found that mothers reported becoming closer to their children after disclosure. This study found that disclosure rates varied according to the age of the child, the mother's stage of infection, and whether the child resided with the mother. Many reasons for disclosure were given, such as educational, wanting to tell the child before they became too ill, and wanting to be honest. Reasons for nondisclosure included believing the child was too young, fear of rejection, and not wanting to burden the child.

### 3.3.6 Disclosure to family

Families may have many different reactions when a member discloses his or her status. Spirig (2002) found that families tend to withdraw from their environment and one or two members provide care without outside support. Families may discriminate against HIV positive members, but become more supportive if they can see something positive. Paxton (2001) found that family reacted negatively to members that disclosed in public, but became more positive once they saw the beneficial consequences of the public disclosure.

### 3.3.7 Public disclosure

Public disclosure has been found to have its pros and cons in the experiences of HIV positive people. Some of the pros include meeting celebrities, traveling, receiving gifts, gaining attention and money, and the opportunity to turn something negative into something positive. Improvements in psychological state and a decrease in isolation have also been reported (Paxton, 2001; FXB center, 1997). However, it has been reported that feelings of exploitation and a loss of privacy are also experienced. Sometimes a negative reaction is given from the public, thus making the individual feel stigmatized (Paxton, 2001; FXB center,

1997). It has been found that for children public disclosure causes a loss of self-esteem rather than a gain in self-esteem as one might expect. Some children tend to view themselves as less scholastically and socially competent after public disclosure (FXB center, 1997).

### 3.3.8 Men's reactions to female partner's disclosure

Although some men may respond positively to their wives or girlfriend's disclosure some respond in very negative ways. Studies have shown that women are at increased risk for partner violence. Maman, Mbwambo, Hogan, Kilonzo, Sweat, and Weiss (2001) found a strong association between HIV positive women and the experience of partner violence, especially for women in the 18 – 29 years age group. Men may respond by rejecting, abandoning, or verbally abusing women (Chadwick, 2003).

Sinkoyi (2000) found that people living with HIV often perceived stigmas to exist, but upon revealing their status found that these stigmas did not always hold true. Those who do disclose may receive unanticipated positive responses as well as the anticipated discrimination. Therefore it is important that individuals move beyond stigma, real or perceived, and find ways of revealing their status and living with it if they are to have positive life experiences (de Bruyn, 1998).

## **4. Psychosocial Issues**

### **4.1 Stigma and Discrimination**

#### 4.1.1 What is stigma and discrimination?

Stewart, Pulerwitz, and Esu-Williams (2002) describe stigma as 'a social process that marginalizes and labels those who are different and discrimination as 'the negative practices that stem from stigma, or enacted stigma'. Stigma and

discrimination may merely be felt or enacted. De Bruyn (1998:1) describes felt stigma as 'the shame associated with the illness and the fear of being discriminated against on the account of the illness' and enacted stigma as 'actual experiences of discrimination'. Many people with HIV have not actually experienced stigma or discrimination, but do not disclose in fear of it, thus preventing them from receiving support and other health care benefits. It remains a fact that while some stigma is merely perceived, most HIV positive people do experience stigma. Stigma is powerful because it changes the way individuals see themselves and others. HIV/AIDS stigma is so unique because of the uniqueness of the virus itself; it has so many dimensions: 'no area of life is untouched by stigma and no area of life is invulnerable to discrimination' (de Bruyn, 1998). Stigma is a central problem-causing factor in the lives of HIV positive people.

#### 4.1.2 After so many years of knowledge of the virus why is there still so much stigma?

The fact that HIV is a life threatening illness with no cure contributes to the stigma. People are afraid of contracting the illness and therefore avoid and fear those who are infected (Fesko, b: 2001; Hodgson, 1999; Herek & Glaunt, 1991; Lynch, 1989). HIV is stigmatized because it is associated with the behaviors of which society does not approve. Hodgson (1999:3) describes HIV as a disease that does not fit the normal profile of disease, as it is complicated by 'unacceptable behaviors'. Homosexuality and intravenous drug use are examples of the behaviors that stigmatize HIV. The majority of society instantly shuns people who contract HIV from engaging in taboo behaviours (Isiaka, Cartoux, Ky-Zerbo, Tiendrebeogo, Meda, Van de Perre, & Dabis, 2001; Sinkoyi, 2000; Travers & Paoletti, 1999). Society often assumes that those infected with HIV deserve it as a punishment for engaging in such behaviors, whether they actually have or not. This view is commonly found amongst those with certain religious or moral beliefs (Hodgson, 1999). They view HIV infection as a result of a moral

ault, such as not abstaining from sex before marriage. It is often considered that being infected is the person's fault or responsibility. Society is generally unsympathetic towards HIV positive individuals, since society sees HIV as an illness from which people can protect themselves (Travers & Paoletti, 1999). These social opinions, fears, and judgments create the stigma, discrimination and fear that HIV positive individuals must face.

## **4.2 Support**

### 4.2.1 Social Support

Research has shown that social support is an enhancer of positive coping (Lindegger & Wood, 1994). In developing countries it is often the only source of care. Those that do not have social support or those who feared being stigmatized may enter a stage of denial (AIDS Alert, 2001), and may not seek information on prevention and treatment nor willing to acknowledge risk-taking behaviors. This coping mechanism of denial for self-protection from stigma means that people do not disclose their status to partners, friends or family and places others at risk (Fesko, a: 2001; Serovich 2001; Issiaka et al., 2001; Sinkoyi, 2000).

Social support is associated with the psychological well-being of HIV positive people and acts as a buffer against stress and depression (Duyan et al., 2001; Serovich, 2001; Leask et al., 1997). Those who feel too stigmatized to disclose their status to family or friends are more likely to experience symptoms of depression. Keeping HIV positive status a secret leads to a life of isolation, depression, and loneliness (Sinkoyi, 2000). Andrews & Novick (1995) found emotional responses play a large role in patients' adherence to treatment recommendations, participation in self-care, and quality of life. Their investigation revealed positive attitudes correlated with improved survival. Further, stress is associated with a lack of social support and this has been shown to have a negative effect on the immune system. It seems that social support can moderate

the effects of stress both psychological and physical. Social support was also found to have importance in obtaining adherence to treatment and medical care (Duyan, et al, 2001; Siegel, Karus, & Schrimshaw, 2000).

Trujillo, O'Brien, Kendall, Hassig, Volle, and Kissinger (2001) found an association between social support and disclosure of HIV status. Their study suggests that people who disclosed were more likely to belong to a support group, and were more likely to have a best friend than those who had not disclosed to family and friends. Once again this illustrates the importance of social support in the lives of HIV positive people.

#### 4.2.2 Family Support

A study conducted by Serovich (2001) revealed that even if family support was only perceived it reduced loneliness, stress, and depressive symptoms. Women who have an understanding family to confide in feel they are able to cope with themselves and their children (Neuvians, 1988). In a study on public disclosure Paxton (2001) found that one of the best sources of support was family.

Stigma and discrimination prevent HIV positive people from obtaining the support they need, often to the detriment of their psychological and physical health.

#### **4.3 Workplace**

Work has been identified as an important contributor to a healthy life for HIV positive people, especially since life-prolonging drugs are more available. Individuals can and want to continue working, instead of retiring as in the past (Fesko, a: 2001; Key & DeNoon, 1997). Returning to work is critical to the needs of HIV positive individuals. Fear and stigma often contribute to HIV positive people not being able to disclose their status at work (Kinniburg et al., 2001;

Sinkoyi, 2000). Disclosure at work, as discussed earlier may provide further more opportunities for social and emotional support (Simoni et al., 2002).

The workplace is an area of difficulty for HIV positive people because of the many opportunities for stigma and discrimination, whether applying for a job, returning to work or working. In a South African study it was found that workers were more concerned about stigma from their colleagues than from employees. Whilst a minority was worried they might be fired if their status became known (Stewart et al., 2002). Employers may do a variety of things to discriminate and stigmatize an HIV positive employee, such as breach confidentiality of the person's status, allow other employees to harass them, or refuse to accommodate special needs (de Bruyn, 1998). Although the law seeks to protect the rights of HIV positive people, it often fails to do so in reality (Chadwick, 2003; AIDS Bulletin, 2001). In South Africa HIV testing without the employees knowledge is increasingly prevalent and employees, especially domestic workers, are 'constructively dismissed', i.e. harassed until they resign (AIDS Bulletin, 2001:1). Many HIV positive people do not take legal action, because they fear further stigma and discrimination (Fesko, 2000). Thus employees and coworkers perpetuate these social stigmas, making it more and more difficult for the HIV positive people that remain in employment.

Zagumny and Deckbar (1995) conducted a study to investigate the willingness of co-workers to work with HIV positive workers and their sympathy for them. This study revealed that more sympathy was shown towards those who did not know their source of infection than for those who were infected through homosexual activity. Those that had been infected by blood transfusion were shown more sympathy than those who were infected through any type of sexual activity.

HIV positive people experience their illness in negative and positive ways not only at home, but at work too.

#### **4.4 Specific issues for:**

##### 4.4.1 Women

Women's experiences of being HIV positive differs from men's, due to the position they hold in society and their biological vulnerability to HIV/AIDS. HIV positive women are often the primary caregivers in families and have to look after infected members, and thus may then neglect their own health (Hankins, 1996; Strebel, 1993). It is particularly stressful looking after an HIV positive child and women may have to take the blame for the child's illness. HIV positive women also have to deal with the choice of whether or not to have children. Due to social status and the worth of children in certain cultures choosing not to have children is not always an option (Moore et al., 1996). Disclosure is very stressful for women because they face significant risks of rejection, abandonment, verbal abuse, and assault (Chadwick, 2003).

Malnutrition and weight loss are common experiences for HIV positive men and women, but may be particularly harmful for women. Society's ideal woman is a thin one, and thus some women and their doctors may not pay much attention to weight loss. This may result in severe health risks and lead to a further drop in CD4 counts (Garcia, 2001).

##### 4.4.2 Men

The average age of infection for men tends to be higher than that for women. Men who respond to HIV in a positive way and feel some responsibility appear to be the exception rather than the norm in many communities (Carovano, 1995). Men appear to be in the position of power in most families and communities and thus often have power over sexual relations, however this power is often misused. Many men continue to engage in risk behaviors, lying to their partners and exploiting those with less power, however, like women, men also have to

face stigma and discrimination (Carovano, 1995).

#### 4.4.3 Children

Although studies have shown children to accept their diagnosis well, as they are resilient, they face a number of difficulties (Chirila et al., 2002; Schrimshaw & Siegel, 2002; FXB center, 1997). Children whose parents are infected and unemployed are often left without money for school fees and food. They may often have to help take care of sick family members as well as themselves (Neuvians, 1988; UNAIDS, 2002). HIV orphans face a number of unique stressors such as stigma, isolation, and instability and may be a risk for a variety of emotionally and behavioral difficulties (Forehand, et al., 2003). Children, like adults, may face discrimination and stigmatization from society. There have been cases where children have been turned away from schools when the community learnt about their HIV status (Moore et al., 1996).

#### 4.4.4 Adolescents

This stage of life represents the period in which people begin to come to terms with sexuality and to experiment with sexual relationships. According to Erik Erickson this is when a sense of identity or sense of self is established (Moore et al., 1996). Moore et al. (1996) state that HIV complicates these issues and seems to exacerbate them. HIV makes it more difficult to experiment with sexuality and makes youth even more self-conscious. Coming to terms with oneself also becomes more complex, especially if one is already part of a 'different' or isolated group, such as gay youth or drug users. An HIV diagnosis may cause gay youth to re-experience feelings of being different from peers. Adolescents may have no support due to dysfunctional families or a lack of access to appropriate health care facilities (Travers & Paoletti, 1999; Moore et al., 1996)

#### 4.4.5 Drug Users

The lives of HIV positive drug users is often more complex than other HIV positive people as their dependency on a substance often leads to further difficulties, such as dangerous drug interactions, noncompliance or adherence to treatments. This group often has no social support due to the nature of their habits and is commonly found living on the streets. Many users may engage in risky behaviours, such as prostitution, to support their habits (Moore et al., 1996).

#### 4.4.6 Homosexual and bisexual People

Gay and Lesbian people's experiences of HIV differ from heterosexual people. Being HIV positive may be experienced as a second coming out. It has been found to be more difficult for this community because they are already prejudiced against. Discrimination may be even greater against gay men as the first cases of HIV were found in this community (de Bryn, 1998). Social isolation, loneliness, and anxiety have been found to be common experiences amongst lesbian, gay, and bisexual youth, especially since they may already have little support from peers and family (Travers & Paoletti, 1999; de Bryn, 1998).

#### **4.5 Sex**

Chadwick (2003:3) states that 'it is common for someone newly diagnosed with HIV to abstain from, or not have sex for some time.' Coleman (2003) reports that people may have no interest in sex for a few weeks or even months. It seems that HIV positive people may feel that sexual activity is taboo, since it is the primary mode of transmission of HIV. It may also become associated with illness and death (Coleman, 2003; Garcia, 2001). It is only once people are able to adapt to their diagnosis that they begin to feel more sexual desire (Coleman, 2003). Garcia (2001) states that realizing that sex does not stop after a

diagnosis of HIV is an important part of facing and adapting to an HIV positive status.

Protection during sex is important for HIV positive people, not only to prevent transmitting the virus to their partner, but also to protect themselves from becoming infected with other sexually transmitted diseases or any other form of HIV. Chadwick (2003) found that non-disclosers were more likely to use condoms than those who had disclosed to their partners. Stigma and denial often prevent the use of condoms (Khoransee, 2001).

## **5. HIV and Psychiatric Disorders**

Psychiatric disorders may become part of an HIV positive person's experience. Adjustment disorders, disturbances of sleep, anxiety, depressed mood, sexual difficulties, suicidal ideation, and changes in appetite are fairly common, especially after a diagnosis of HIV (Coleman, 2003).

### **5.1 Depression**

The prevalence of mood disorders amongst HIV positive people varies from study to study (Aids Alliance, 2003). Valente (2003) reports depressive disorders to be common among 20 – 32% of HIV positive people and that it is frequently unrecognized. Further, according to Valente (2003), those with a history of intravenous drug use have increased rates of depressive disorders. Garcia (2001) states that HIV positive women have higher rates of depression than the HIV negative population, possibly partly due to hormonal changes and the negative experiences specific to women living with HIV. Depression may be found in children, particularly after diagnosis. This usually disappears if the child is given support and allowed to explore worries and fears (FXB center, 1997). Moore et al. (1996) report depression following an HIV diagnosis to be common in both young and old. Further they state that it may be short term or long term and that short term tends to be reactive depression.

Depression impacts on adherence to and continuation of therapy and thus may adversely affect the course of the disease and mortality rates (Aids Alliance, 2003). Several studies have shown an increased rate of suicidal ideation, attempts, and contemplation amongst HIV positive people (Karasic & Dilley, 1998; Wicks, 1997). Karasic and Dilley (1998: 2) state 'the belief in the option of suicide may help the person with HIV have a sense of control- that he or she has some choice over the amount of suffering or disfigurement he or she will have to bear'. Both HIV positive men and women that continue to practice unprotected intercourse are more likely to be depressed than HIV positive men and women who practice safer sex (Kalichman, 2002). Untreated depression may increase medical expenses, cause substance abuse and risky behaviors, such as unprotected sex, and reduce compliance with treatment and quality of life (Valente, 2003; Angelino, 2002).

Some small studies have shown that depression in HIV positive people is linked to low levels of testosterone, which affects mood, energy, weight, and sexual arousal. (Aids Alliance, 2003)

The diagnosis of depression is complicated by the fact that many symptoms of depression are also part of the physical symptoms of HIV. HIV positive people may experience periods of depression due to psychological stressors from coping with HIV.

## **5.2 Anxiety**

*Anxiety is commonly experienced when HIV is first diagnosed (Coleman, 2003).* When adapting to HIV-related stressors, periods of anxiety are considered to be normal. If symptoms of anxiety, such as persistent discomfort, preoccupation with anxiety continue, then treatment may become necessary (Karasic & Dilley, 1998;

Moore et al. 1996). Anxiety has been found to correlate with high-risk sexual practices among HIV positive men (Kalichman, 2002).

### **5.3 Insomnia**

Insomnia may also be part of an HIV positive person's experience. It may be a result of an anxiety or depressive disorder, but there is also some evidence of insomnia being organically part of HIV (Karasic & Dilley, 1998; Moore et al., 1996).

### **5.4 Bereavement**

HIV positive people usually experience bereavement (Moore et al., 1996). They may grieve for multiple losses of partners, friends, or family members as well as elements of themselves, such as body image, job, and long-term goals.

However, most learn to adapt to the loss within several weeks; it is usually only those with poor coping skills and poor social support that need treatment for grief (Karasic & Dilley, 1998; Moore et al., 1996).

## **6. Antiretrovirals**

Many people, especially in South Africa, are unable to take antiretrovirals due to the costs of this medication. Those that do take antiretrovirals face associated challenges. Side effects, such as changes in body shape to heart disease, drug schedules, and costs are examples of some of these associated challenges (Garcia, 2001; Catz, McClure, Jones, & Brantley, 1999). Despite these challenges, many HIV positive people express positive feelings about taking these drugs as they feel that they improve their prospects (Ezzy & de Visser, 2000).

Many people miss taking their medication because of the fears of taking them in public and the difficulty of integrating them into their daily activities (Golin, Isasi, Bontempi, & Eng, 2002). The amount of pills that one is required to take may just be too overwhelming for some people and thus led to the skipping of doses. Some treatments require 20 to 30 pills to be taken on a daily basis at specific times. A study found several psychosocial factors, such as elevated depression, side effects, low perceived confidence in ability to adhere, and low perceived social support, that are linked to greater likelihood of missing highly-active antiretroviral therapy or HAART (Catz et al., 1999).

## **7. Income and Productivity**

Many HIV positive people find themselves having increased costs and being capable of less work. This leads to a variety of problems. Necessities, such as housing, clothing, medication and food, may no longer be obtainable. This is especially true in poorer communities where there are already shortages of the basics (UNAIDS, 2002).

## **8. Conclusion**

HIV affects every area of life and each individual differently. Experiences of HIV positive people thus vary and depend upon a large number of factors, such as gender, sexual orientation, and financial status. Stigma and discrimination, whether enacted or felt, are still a large part of HIV positive people's experiences and often determine whether people disclose their status or not. From this review of literature it seems that the more support HIV positive people have the better their experiences of health and life.

## **CHAPTER 3 – METHODOLOGY**

### **1. Introduction**

Much has been written about HIV from a medical perspective and from a human rights perspective, but it seems that little has been written on the actual experience of what it is like to live with HIV. This research provides an opportunity for HIV positive South Africans to express themselves and for the rest of the population to gain insight into the actual experience of living with HIV.

A quantitative approach requires one to pre-select themes or categories, thus it presumes beforehand what an HIV positive person experiences, whereas a qualitative approach seems more appropriate as it may be used to elicit themes without making any assumptions, and thereby providing a clearer expression of what it is like to live with HIV. Giorgi (1994) argues that by not providing pre-described reality or specifications, things that were not considered are given a chance to be discovered. Further, it seems that the qualitative approach, from a Phenomenological perspective, is best suited to doing just this as the Phenomenological method requires the researcher to provide an accurate description of the phenomena without attempting to explain it by using any theories or systems.

### **2. Methodological orientation**

The Phenomenological method gives priority to the phenomena under study, rather than secondary established methods. Instead of reducing or limiting a phenomenon to the basics, the world as well as the individual are included thereby ensuring no meaning is lost (Stones, 1986). As Phenomenology studies how participants express what they experience, and this is determined only by how the participants have experienced the phenomena, no objective reality is assumed. Yet this method assumes that a commonality or commonalities are

found in shared experiences. Phenomenology therefore seeks to describe these commonalities, without referring to secondary methods or assuming an objective reality. Instead it endeavors to bracket or put aside any preconceived ideas and attitudes, allowing commonalities in experiences to be revealed and described (Ashworth, 1996).

The operative word in the Phenomenological method is 'describe', rather than explain, as this method attempts to describe experiences in their purest form, without contaminating them by attempting to force findings into predetermined categories or theory (Kruger, 1979). Polkinghorne (1989: 45, as cited in Vaille and Halling, 1989) aptly describes what this method endeavors to achieve: 'Instead of studying the body as an organic object, it studies the experiences people have of their bodies'.

Terre Blanche and Kelly (1999) place Phenomenology under the umbrella of interpretive analysis. Terre Blanche and Durrheim (1999:123) describe interpretive analysis as an approach that 'tries to harness and extend the power of ordinary language and expression, developed over thousands of years, to help us better understand the social world.' Kelly (1999:415), states that this method is not 'a mechanical process', but rather one of enquiry, where there are no set rules, only guidelines.

The Phenomenological method does not aim to draw inferences from a sample and apply them to a population, nor does it attempt to describe the characteristics of a group. Instead this method attempts to describe the structures of an experience. Further, it seeks to describe subject's meanings, instead of just actions or behaviours. Polkinghorne (1989: 50) states that the aim of Phenomenology is to 'reveal and unravel the structures, logic, and interrelationships that obtain in the phenomena under inspection'. It seems that Phenomenology does not emphasis generalizability, but rather focuses on the quality of experiences (Kruger, 1979).

Validity and reliability of findings are of concern to most researchers. Kruger (1979) requires procedures to be made overt in order for other researchers to replicate the research if so desired. It appears that Kruger (1979) addresses the question of reliability and validity of this method by emphasizing the importance of the reappearance of various themes, rather than reliability and validity depending upon reliability only. According to Polkinghorne (1989), the degree of validity is found in the degree to which the research is able to convince the reader of the accuracy of the findings. In addition to readers feeling convinced by the presentation, those readers who have experienced the phenomena must agree that the findings correspond with their experiences. Therefore, for research findings to be considered to be valid and reliable, they must provide an accurate representation of common features and structures as found in other research and in people's experiences.

### **3. Participants**

This phenomenological investigation focuses on the experiences of 6 HIV positive participants. Necessary details about each participant and their stories may be found in appendix A.

It was not possible to obtain participants from one location. Many organizations and colleagues were approached to provide consenting participants or sources where participants could possibly be found. Sadly, very few organizations were willing to approach clients as they felt it to be 'too sensitive an issue'. Stories came from a 'snowballing effect' whereby I was put in contact with an HIV positive person or organization and they then contacted others. Most stories were obtained through e-mail. Organizations that provided assistance were National Ports Authority and Triangle Project. A colleague, with the permission of her clients, provided two stories.

Purposeful sampling was applied to choose suitable participants, as this method requires the selection of knowledgeable and informative participants, which hopefully ensures rich, insightful material. In addition to this sampling method, Stones' suggestion for the selection of participants was applied:

- have had experience relating to the phenomena to be researched
- are verbally fluent and able to communicate their feelings, thoughts, and perceptions in relation to the researched phenomena
- express a willingness to be open to the researcher
- are naïve with respect to psychological theory (1986:120)

#### **4. Design and data collection**

Participants were asked to write about their experiences of what it is like to be HIV positive and these stories are available in appendix A. No identifying data was required, only age, name, and gender were requested. Participants were free to write as long or short a story as they pleased. Informed consent was explained to participants. A written consent form was not used, as most participants did not feel comfortable signing their names. In addition, some stories were obtained through e-mail, making it impossible to sign a consent form.

#### **5. Analysis and interpretation**

The following are steps, as suggested by Terre Blanche and Kelly (1999), were used to guide this study in analysis and interpretation of the stories:

##### **Step 1. Familiarization and immersion:**

This step involves making oneself familiar with the texts by several readings of the texts as well as brainstorming and note and diagram making. Thus this step

should allow one to have an idea of what can be found, where they may be located, as well as some of the interpretations that may or may not be supported by the data.

### **Step 2. Inducing themes:**

Step 2 involves using what Terre Blanche and Kelly (1999:141) refer to as a 'bottom-up approach', whereby organizing principles are worked out from the material, instead of using preselected categories. They suggest using the language of the participants rather than theoretical language to label categories. Secondly, when selecting themes one should not only summarize content, but rather look at contradictions, functions, tensions, etc to organize the material. Thirdly, it is necessary to find an 'optimal level of complexity' (Terre Blanche & Kelly 1999:142), meaning the correct amount of themes must be selected for discussion. Fourthly, they suggested not settling on one system, but playing around to find the best one. Lastly, it is important to keep focus on what you are trying to research so that only relevant themes are selected.

### **Step 3. Coding:**

Coding refers to marking data that is relevant to one or more themes. Coding for this study was done by highlighting relevant bits of text in different colours. Each colour represented a theme.

### **Step 4. Elaboration:**

From the coding process new themes and issues may arise when examined more closely and this is referred to as elaboration. Thus things that may previously have been undetected are now seen and this may lead to a refinement of previous coding systems. Terre Blanche and Kelly (1999), suggest

that coding, elaboration and recoding should continue until there are no new significant changes.

#### Step 5. Interpretation and checking:

This step is the final one, where an account of the phenomena is written using thematic categories for headings. This step allows interpretations to be carefully explored and if necessary corrected or improved. It is also suggested that the researcher's involvement that may have biased the data should be reflected upon. This was included under limitations of the study.

Using Terre Blanche and Kelly (1999), suggested steps data analysis was performed. The stories were then read twice in order to gain familiarity with them. In the initial reading of the stories an attempt was made to bracket out personal preconceptions and judgments as much as possible. A second reading involved a more reflective attitude. The stories were then broken down into themes, without interpreting or changing the subject's meaning as congruent with the phenomenological methodology (Stones, 1986). As suggested by Terre Blanche and Kelly (1999), and Miles and Huberman (1994), each story's themes were organized into a visual display and an example may be found in appendix B. Each theme was written in a different colour so that text supporting the theme could be marked and easily identified. Chapter 4 will present the themes taken from the stories in the form of a table for the reader's convenience. In addition the main themes, i.e. those to be discussed in chapter 5, are highlighted in bold. The main themes represent those that were found in at least half of the stories. These themes were then discussed in chapter 5 in relation to literature.

To facilitate a deeper understanding and interpretation of the themes Parker's (1992) understanding of discourse analysis became a useful framework.

Therefore a brief discussion of discourse analysis is necessary.

## 6. Discourse analysis

Durrheim (1997) describes discontentment in psychology and other social sciences as the empiricist model has not managed to find ways of predicting or controlling human behavior as was intended. He states that the change to social constructionism from empiricism is partly due to recognition that the empiricist model of science is not appropriate for research in psychology. Durrheim (1997) argues for discourse analysis as an appropriate social constructionist method since it appears to address inadequacies found in empiricist science and psychology. Discourse analysis moves beyond what Durrheim (1997: 181) describes as 'the mechanistic, dualistic, and individualistic understanding of their object of study'. Thus discourse analysis goes further than description to interpretation. In fact this method moves beyond phenomenology, as it does not only consider individual constructions, but rather looks at the social and historical background in which these constructions were formed. Thus, as argued by Parker (1992:92), discourse analysis treats the social world as a text or system of texts. Parker (1992:5) suggests the following criteria for consideration when using discourse analysis:

- A discourse is realized in texts, which can be in any form (spoken, written or enacted).
- A discourse is about objects, including talk about talk (discourse) as if it were an object.
- A discourse contains subjects (e.g. reader of a text) which may also have been identified as the objects of that discourse.
- A discourse is a coherent system of meanings, in so far as the statements in it refer to the same topic or theme. "Different slants on the discourse" – may be given by different "competing cultures" ranging from those whom the discourse benefits to those whom it oppresses.

- A discourse reflects on its own a way of speaking. Indications of this happening are, for example, when people talk about “race in inverted commas” or use the phrase “for the need of a better word.”
- A discourse refers to other discourses, as when a discourse may also indicate that other discourses are being referred to. It therefore is important to see the inter-relationship between different discourses.
- A discourse is historically situated and dynamic – one needs to see how and when a discourse emerged and how it changed.

Parker (1992:37) states ‘When we want to understand the function of a particular discourse, the way they position their subjects in relations of contempt and respect, of domination and subordination or the opposition and resistance, we pass quickly and ineluctably from conceptual critique to social critique’. Thus discourse analysis is useful in that it provides more than just an understanding of how an individual has constructed meanings of an experience, it allows us to examine how society and language have shaped these experiences.

Chapter 4 will provide the themes that emerged from the stories. Chapter 5 attempts to discuss and understand the themes in light of the reviewed literature. Further, discourse analysis will be used to understand how subjects constructed meanings from their experience of living with HIV and how they positioned themselves within their experience.)

## CHAPTER 4 – RESULTS

### 1. Introduction

The following chapter will present the themes identified from the stories through the phenomenological method, as described in chapter 3. However only the main themes will be justified and, in chapter 5, discussed in greater detail in relation to the literature. Many themes overlap, but for the purpose of this study, will be discussed separately.

### 2. Themes

The table below displays the themes found in the stories. Main themes are highlighted in bold. Main themes are considered to be those found in 3 or more of the stories and they will be the focus of this chapter.

<b>Themes</b>	<u>Participant</u> <b>1</b>	<u>Participant</u> <b>2</b>	<u>Participant</u> <b>3</b>	<u>Participant</u> <b>4</b>	<u>Participant</u> <b>5</b>	<u>Participant</u> <b>6</b>	<b>Total</b>
Disclosure	<b>1</b>	<b>1</b>	<b>1</b>	<b>1</b>	<b>1</b>	<b>1</b>	<b>6</b>
Stigma	<b>1</b>	<b>1</b>	<b>1</b>	<b>1</b>	<b>1</b>		<b>5</b>
Denial		<b>1</b>	<b>1</b>	<b>1</b>	<b>1</b>	<b>1</b>	<b>5</b>
Physical Symptoms	<b>1</b>	<b>1</b>	<b>1</b>	<b>1</b>	<b>1</b>		<b>5</b>
Symbolic representations of HIV/AIDS	<b>1</b>	<b>1</b>		<b>1</b>		<b>1</b>	<b>4</b>
Medication	<b>1</b>	<b>1</b>		<b>1</b>	<b>1</b>		<b>4</b>
Depression		<b>1</b>	<b>1</b>	<b>1</b>		<b>1</b>	<b>4</b>
<b>Anger</b>	<b>1</b>				<b>1</b>	<b>1</b>	<b>3</b>
Death			<b>1</b>	<b>1</b>		<b>1</b>	<b>3</b>

Risk taking	1				1		2
Time	1					1	2
Religion		1	1				2
Survivor	1	1					2
Disempowerment	1					1	2
<b>Isolation</b>			1			1	2
Hope		1					1
<b>Hopelessness</b>						1	1
Education		1					1
Helplessness	1						1

### 3. Main themes

#### 3.1 Disclosure

The theme of disclosure refers to individuals' decision to reveal or not reveal their HIV positive status to others. Disclosure was present in every story and thus a significant part of each participant's experience of living with HIV. It appears that disclosure may help share the burden of the illness as it provides some support for the ill, but may also be negative due to stigma and discrimination.

Disclosure seems to bring about a dilemma for most participants as they are unsure who to disclose to and fear the possible consequences of their disclosure. The following extract illustrates the dilemma in disclosure:

Extract 1:

'My big daughter sees that I am not well. I don't really want to tell her what I have. I will tell her soon' (Participant 3).

All participants disclosed to at least one person, often a family member, as shown in these extracts:

Extract 2:

'My sister, she is a nurse so she knows what is wrong with me' (Participant 4).

Extract 3:

'My mother and psychologist know, as well as my new boyfriend who decided to stay with me' (Participant 6).

Extract 4:

'My mother knows I have AIDS/HIV but my friends don't' (Participant 3).

From the above extracts one may hypothesize that disclosure is usually only to family members or certain significant others and not friends due to fears of rejection and stigma from society. This is particularly evident in extract where the participant implies her mother will accept her, whilst her friends may reject her. Further, it seems that while disclosure to family has benefits, it is also necessary to include those in the medical profession, for example in extract 2 the participant mentions a psychologist. These professionals appear to provide an intimacy that makes disclosure to them somehow easier or acceptable for HIV positive people. Perhaps this intimacy or acceptability arises from the unconditional positive regard and non-judgmental stance taken by professionals, such as the psychologist and thus results in a greater opportunity for help in managing and treating the individuals' emotional and physical well being.

However, it seems that the people chosen for disclosure are not always family members, close friends, or medical professionals, as seen in the following extract:

Extract 5:

'When I was diagnosed with Aids a few months ago, I confided my status to a very close friend. He was one of the friends that through the grapevine I suspected of being HIV+. I never had the guts to ask him about his status before and I don't think he really discussed his status with any of his friends. But when I told him about myself, he told me that he tested positive eleven years ago. At that stage nobody spoke about it in this country' (Participant 1).

From the above extract it seems that disclosure took place not only because of perceived support or expert knowledge, but also because of a suspicion that his friend shared the same secret. It seems that by sharing the secret of an HIV positive diagnosis it becomes safer to disclose, as seen in the above extract. Further, disclosure appears to be avoided because of fears of stigma, thus an HIV positive status may be kept secret for several years, as illustrated in the above extract. However, there appears to be some contradiction in this extract. The participant calls the person he confided in 'a very close friend', but yet he 'never had the guts to ask him about his status before' and he heard it 'through the grapevine', which seems to imply they were not as close as he suggests. It appears disclosure took place because there was suspicion that the other person's status had already been disclosed, rather than their relation to one another or any particular need.

In addition, from extract 4, it appears HIV positive people may rationalize and justify their choice as to whether or not to disclose and to whom to disclose to. In extract 4 it seems the participant justifies his friend keeping the secret for so long, as suggested by the following example 'At that stage nobody spoke about it in this country'. Perhaps these defenses allow HIV positive people to somehow

distance themselves from the responsibility of fighting the stigma and discrimination they fear. Further, it appears that these defenses allow them to not face these fears; by keeping one's status a secret one does not have to worry about being rejected or facing stigma and discrimination. However, these defenses may be used to justify disclosure, as seen in this extract:

Extract 6:

'At that stage I realized that if I keep this a secret, it was going to destroy my immune system. I believe that when I talk about it, that it heals I am also frustrating it. I can live longer if I am living a positive life. Because with HIV/AIDS, even though it is in your body, your mind must be liberated. That is reason I decided to disclose my status' (Participant 2).

Extract 6 reveals disclosure to be this participant's survival strategy or coping mechanism. This participant seems to associate disclosure with an element of healing and power, i.e. disclosure helps him to fight the virus by using his mind to focus on living a positive life, rather than negative consequences such as death. It gives the impression that disclosure may also be articulated to fulfill a particular need. This need may be a need for providing a way of living with the virus.

Disclosure may take place for other reasons, such as financial, as demonstrated by this extract:

Extract 7:

'My brother knows because he gives money to my mother to help look after the children' (Participant 3).

However non-disclosure also seems to fulfill a need or role. From the following extracts it seems that non-disclosure allows the subject to escape responsibility and thus avoid facing the virus:

Extract 8:

'I will only tell them when they get sick, they won't know they got it from me I will say I got it from them' (Participant 5).

Therefore, by not disclosing he is able to almost forget about the virus, as he will only have to own it when his partners discover their statuses. Thus it seems that non-disclosure allows for a kind of denial and provides some sort of false comfort or a way of living with the virus. Further, it somehow exonerates him from taking responsibility for infecting them.

For some participants not disclosing appeared to offer them protection from the outside world. It helps them to avoid facing the stigma and discrimination they fear, real or perceived. In this way non-disclosure offers a shield from possible struggles, as demonstrated by the extracts 9 and 10:

Extract 9:

'I used to work but now I can't I can't tell my work because if they think I have this sickness they won't take me back' (Participant 3).

Extract 10:

'I haven't told the school where I work what is wrong with me. I don't think I am going to tell them unless I have to have too much time off. My friends don't know that I am sick I am not going to tell them. There is too much trouble the people would stone us' (Participant 4).

It appears that this theme is a central issue and enters many areas of experiences for these HIV positive people. This theme will be discussed further in chapter 5. Stigma and disclosure are often coupled together; stigma appears to represent the fears involved in disclosing one's status to others as well as a justification for non-disclosure.

### 3.2 Stigma

The theme of stigma is present in most stories and represents fears associated with HIV such as a fear of unjust treatment, of isolation or rejection, of being physically harmed, and of losing employment. This theme also includes societies' judgments and prejudices. In addition, it seems that stigma has an influence on disclosure, as it is often used to justify why participants have or have not disclosed. The following extracts are examples of stigma as described by the above discussion:

Extract 11:

'I can't tell people because I know they will treat me badly' (Participant 6).

Extract 12:

'I used to work but now I can't I can't tell my work because if they think I have this sickness they won't take me back' (Participant 3).

Extract 13:

'My friends don't know that I am sick I am not going to tell them. There is too much trouble the people would stone us' (Participant 4).

The above extract really illustrates the fear and seriousness associated with disclosing that one is HIV positive. It seems that the stigma associated with HIV could lead to a very violent, painful death. In addition it illustrates the power of stigma; people may do something so violent just because one has an illness they fear. Stoning is usually a group activity, reflecting a group decision. Stigma separates one from the group as one can no longer share the same opinions or partake in the same judgments. Stigma may create the need for isolation, not only because one is now different from the group, but also for protection from possible stigma-informed group action against one.

Stigma may be used for more than reasons for non-disclosure and isolation. One participant used the voice of stigma to almost distance himself from the virus and to blame others, as shown by the following extract:

Extract 14:

'I will not tell my friends or workers that I have AIDS they will think I am sleeping with blacks' (Participant 5).

Further, the above extract may reflect that South Africans perceive HIV as a disease belonging mainly to black South Africans. Thus, some South Africans may be said to view HIV in racial terms.

The theme of stigma appears to be vital in determining how people are living with HIV. Those that fear it do not disclose and often isolate themselves in order to protect themselves. Stigma may be used to shift responsibility or blame onto others and seems to be a reflection of society's attitudes towards HIV. It seems that society may view HIV positive people as deserving of violent death and belonging to black South Africans. Thus, stigma appears to be a powerful tool in shaping HIV positive people's lives.

### 3.3 Denial

Denial refers to a defensive strategy or a "pseudo acceptance" used to avoid the emotional "baggage" as well as issues, such as death and stigma, which often accompanies this illness. Participants stated an acceptance of the virus, but then minimized it into an almost curable, normal disease. In addition, participants tended to deny the seriousness of the virus by using defenses, such as rationalization, intellectualization, and justification. The following extract demonstrates this:

Extract 15:

'I have no doubt that I have Aids. All the symptoms I had last year were Aids related. I also know that many people who had these symptoms and related diseases have died from this. On the other hand if I look at the number of people in the Western world who have died of Aids in the last twenty years and the number of people currently HIV+, I come up with a very small minority of the infected pool who have actually died. [In Sub-Saharan Africa the situation looks very different, but there millions of people don't even have running water or proper nutrition. How can they be expected to survive?] I know the argument is that the majority of HIV infections only took place in the last few years and that the future predictions for Aids deaths therefore look catastrophic' (Participant 1).

This participant suggests that '...a very small minority of the infected pool who have actually died'; in this he minimizes the seriousness of HIV/AIDS. He goes on to intellectualize by discussing socio-economic factors, such as no running water, and rationalizes their death rate from HIV by asking 'How can they be expected to survive?'

Denial was also expressed more directly, as illustrated by this extract:

Extract 16:

'I have been sick for one year. I don't think I am going to die I will get better. I have accepted the sickness; I was counseled at the clinic before I got my results. My mother also told me I must accept it.' (Participant 3)

Other participants used the "stigmatized profile" of how an HIV positive person should look; sickly and very thin, to deny the seriousness of the virus, as shown by the following extracts:

Extract 17:

'I have not told him I am sick. He does not look sick but I think he must be'  
(Participant 4).

Extract 18:

'Anyway I feel better now that I have the drugs nobody can see that I am sick. I think I will live a long time' (Participant 5).

### 3.4 Physical Symptoms

Physical symptoms refer directly to the illnesses associated with an HIV positive diagnosis. It appears that an emphasis on physical symptoms perhaps allowed participants to avoid the emotional pain that such an illness may bring. Further, by focusing on physical symptoms perhaps the disease becomes more treatable, rather than incurable and unknown. The following extracts illustrate the focus on these symptoms:

Extract 19:

'I firstly felt very ill I had an unstoppable running stomach, headache, sweating, loss of appetite and felt very tired' (Participant 2).

Extract 20:

'I started to feel really tired at the beginning of the year and lost a lot of weight. At first I was pleased because I was getting to fat. I soon started to get scared because I kept losing weight and I got a rash on my skin and my mouth'  
(Participant 5).

Extract 21:

'I don't feel good. I feel all black inside my kidney's feel heavy and black. I can't hold things my hands don't work properly and I can't work either' (Participant 3).

It seems that physical symptoms act as a trigger for initial diagnosis, as seen in these extracts:

Extract 22:

'I firstly felt very ill I had an unstoppable running stomach, headache, sweating, lost of appetite and felt very tired. One morning I decided to go to Hospital and seek for treatment. Fortunately the Doctor knew about the symptoms of HIV/ AIDS' (Participant 2).

Extract 23:

'I only went for an Aids test when I started getting ill last year' (Participant 1).

Physical symptoms appear to be a powerful theme in that it influenced many participants' behaviors, such as disclosure and sex, as well as decisions, such as deciding to engage in risky behaviours, as shown by this extract:

Extract 24:

'I felt that if he could have a deadly disease and still look that healthy and sexy, I wouldn't mind having it with him... He was so intent on playing it safe when we were together that I actually became irritated with all the precautionary measures' (Subject 1).

The above extract illustrates how the lack of obvious physical symptoms may be used to rationalize decisions or desires to engage in risky behaviours, such as unprotected sex. It seems that the tension between physical appearance and lack of physical symptoms of the disease and the presence of HIV provide a dangerous, but exciting opportunity to share in something, or perhaps carry the burden of illness together. In addition, a healthy appearance appears to make the virus more acceptable as it allows for denial of serious illness and the images provided by society of what an HIV positive person should look like. Therefore,

as mentioned previously, physical symptoms may allow for a denial of the seriousness of HIV.

### 3.5 Symbolic representations of HIV/AIDS

HIV/AIDS appeared to be a theme on its own, as many participants experienced it as something almost tangible, something that they could separate from the self and the fight. HIV/AIDS seems to be referred to in a metaphorical way, as though the virus is a living, thinking being as opposed to a small virus, only observable under a microscope. HIV/AIDS appears to be given an identity of its' own, one that is beyond the medical definition and many participants appeared to have their own way of combating their metaphorical enemies. These included ways such as exposing it to the world through talk or by fighting it with a positive attitude, all means designed to suit their own perceptions of the HIV/AIDS living inside of them rather than suggestions from science. These extracts illustrate the above discussion:

Extract 25:

'I feel like this thing is eating me, I am very weak.' (Participant 4)

Extract 26:

'I believe that when I talk about it, that it heals I am also frustrating it' (Participant 2);

Extract 27:

'This thing is going to kill me if I let it, I just don't know if I can stop it' (Participant 6);

Extract 28:

'I stay positive because I know I can beat this thing' (Participant 3).

### 3.6 Medication

Medication arises in the majority of the stories and thus deserves some attention. This theme is used to refer directly to medications given to fight HIV/AIDS and indirectly to the medical professionals. For many, medication seems to resemble some hope of survival, as shown by these extracts:

Extract 29:

'I think that now I have the medicine I won't die' (Participant 4);

Extract 30:

'I think that I will live a long time with the drugs they give me' (Participant 5).

Medication also appears to be used as an escape from facing the seriousness of HIV/AIDS, more specifically death, as medication helps to keep the recipient healthy, as the following extract illustrates:

Extract 31:

'Anyway I feel better now that I have the drugs nobody can see that I am sick. I think I will live a long time' (Participant 5).

Thus, it seems to allow participants to hide HIV from themselves, families, friends, and work and avoid social stigma. It also allows them to live in denial, especially if they look and feel well physically, as shown by this extract:

Extract 32:

'The other day I went to see my doctor about the advisability of continuing with anti-retroviral therapy since I'm not sick anymore. I started taking them when I was diagnosed with Aids last year. I feel very healthy at the moment, but get unpleasant side effects from the chemical anti-retrovirals' (Participant 1).

Further, it appears that medical professionals play an important role in the experience of HIV positive people. They seem to have some power in shaping people's experiences of living with HIV. The following extracts illustrate how medical professionals can change how one feels about one's self in relation to HIV/AIDS:

Extract 33:

'Who am I to challenge a doctor who specialises in this condition? What do I know about my own body? This syndrome was identified and proven under a microscope and the signs your body gives you can't be relied on anymore. Science is almighty and the human body knows nothing. Only a medical doctor can tell you when you will live and when you will die. Who has the guts to take his life in his own hands by discontinuing anti-retroviral therapy when the doctor is absolutely sure that you will die? Not me!' (Participant 1).

Extract 34:

'I have medicine they told me I can take it from tomorrow' (Participant 4).

Medical professionals seem to have the power to influence feelings of well-being as well as attitudes and reactions to an HIV positive diagnosis. Further, professionals appear to hold the key to life for many, as they are the ones who determine when one is allowed to take the life prolonging drugs and when one is near death's door. However, it appears that medical professionals may leave some patients feeling disempowered as they possess knowledge and expertise that no one else can provide, thus forcing HIV positive people to rely on them without asking questions.

There also seems to be some influence in terms of emphasis on the physical rather than the emotional side of HIV/AIDS. These medical professionals seem to concentrate on medication and the physical, thus they do not appear to

orientate their patients to the importance of the emotional aspects of HIV/AIDS, as shown by the following extract:

Extract 35:

'I went again to hospital to get the results and the doctor told me I am HIV positive and there is no cure for AIDS so I can go home. And again I didn't get a counseling' (Participant 2).

### 3.7 Depression

Depression was found to be a common theme in just over half of the stories. This theme was based upon descriptions suggestive of the symptoms of depression as described by the DSM IV classification system. Depression appears to represent feelings of hopelessness, suicidal ideation, bitterness towards the virus, as well as a fear of living with the virus and a fear of dying from it, as shown by these extracts:

Extract 36:

'I still feel bad, I am 24 yrs old and I don't have a future. ...I feel dead inside and it is hard to come to work everyday. ... There is nothing else now my life will be short' (Participant 6).

Extract 37:

'When I arrived at home I didn't know what to do that is when I planned to commit suicide' (Participant 2).

A sense of carrying a burden seems to be present. Depression appears to be represented symbolically as something black and heavy; HIV/AIDS and feelings (depression) seem to merge into one burden in the body, as shown by the following examples:

Extract 38:

'I feel heavy inside everything is too heavy' (Participant 4);

Extract 39:

'I don't feel good. I feel all black inside my kidney's feel heavy and black'  
(Participant 3).

From the above extracts it appears that depression and physical symptoms may have a vice-versa effect on one another, i.e. the sicker one feels physically the more depressed one becomes, and the more depressed one becomes the sicker one feels physically. Thus it seems that there is a definite link between depression and the body for these subjects; their bodies appear to symbolically express their depression and thus feelings toward the HIV.

Extract 40:

'Its interesting that I also experienced hardship and failure in the most important sectors of my life at the time when I became ill. Mentally and emotionally my life basically came to an end at the time. That period is over now and I'm sure anti-retroviral therapy as well as antibiotics played a major role in helping me get through it on a physical level' (Participant 1).

The above extract seems to show this participant's depression, however he cannot seem to link HIV with the physical and emotional experiences. It seems that he denies the virus as having part of his depression. Instead he uses depression as a reason for his deterioration. He counters his depression by placing faith in medication and minimizing the virus to something physical that one can recover from.

There appears to be a link between the physical and emotional expression of the experiences of HIV.

### 3.8 Anger

The theme of anger arose in half of the stories. Anger was directed at the source of infection and seemed to create a need for revenge, as demonstrated in the following extracts:

Extract 41:

'I feel strong but angry at the Chinese woman who gave me this illness, she deserves to die' (Participant 5);

Extract 42:

'I don't want to die but I hope he does' (Participant 6).

Anger also appears to represent helplessness and fear. This seems to stem from acknowledgement that although the medical profession has a lot of power in prolonging life they have not found a cure as yet and thus provide a false hope that one is forced to trust due to lack of alternatives, as shown by the following extract:

Extract 43:

'This syndrome was identified and proven under a microscope and the signs your body gives you can't be relied on anymore. Science is almighty and the human body knows nothing. Only a medical doctor can tell you when you will live and when you will die' (Participant 1).

Thus, as evident in the above extracts, this theme of anger may be representative of feelings of disempowerment by the sources of infection, by HIV/AIDS, as well as the medical professionals who seem so powerful, but yet cannot really help you.

### 3.9 Death

Death appears to be something that most participants mention, but avoid as much as possible. It is a theme that seems to elicit a lot of uncertainty, ambivalence, and fear, as revealed by the following extracts:

Extract 44:

'This thing is going to kill me if I let it, I just don't know if I can stop it' (Participant 6);

Extract 45:

'I think that now I have the medicine I won't die. All the nurses tell me to stay positive I just feel very tired. I don't think I will die' (Participant 4);

Extract 46:

'I feel I can get better I never tell myself I am going to die I go to the Nazareth church I haven't told them I am sick' (Participant 3).

These extracts seem to reveal a dilemma caused by contemplation of death. The uncertainty over control of the virus appears to lend people to a situation of almost contradictory feelings, whereby they feel they can stop the virus, but at the same time express uncertainty at achieving this. In addition, there seems to be some fear in even allowing death to come into complete and conscious consideration. Most participants do not allow themselves to even think they are going to die from the virus. Instead they choose to focus on more positive thoughts or ways of living, such as religion.

## **4. Summary**

From the above discussion it seems that HIV brings many challenges, defenses, and coping mechanisms into the lives of HIV positive people. While themes may be discussed as separate entities, there are a number of important overlaps that may have serious implications for how people experience living with HIV.

Chapter 5 will attempt to discuss these themes in greater detail, using existing literature and interpretation, as described in chapter 3.

## **CHAPTER 5 - DISCUSSION**

### **1. Introduction**

This chapter endeavors to discuss the main themes in relation to existing literature and by using interpretation, as described in chapter 3. The main, common themes extracted from the stories reflect the different issues as well as coping mechanisms or “strategy for survival” that constitutes the experiences of HIV positive people. Extracts referred to in this chapter may be found in chapter 4.

### **2. Discussion of main themes**

#### **2.1 Disclosure**

Disclosure referred to the decision whether to disclose or not. It also included to whom subjects disclosed. Levy et al. (1999) have cited disclosure as a measure of people’s acceptance of their diagnosis. The results of this study found that all subjects did disclose to someone and it did seem to reflect a level of acceptance. Levy et al.’s (1999) study found that disclosure was a way of releasing tension. However, this study found that disclosure goes beyond just fulfilling the need of releasing tension as people disclosed in order to fulfil financial and medical needs too, as shown in extracts 5 - 9.

In the literature there seems to be a lot of evidence for the negative effects of non-disclosure (Serovich, 2001; Sinkoyi, 2000; Travers & Paoletti, 1999; Key et al. 1998; Leask et al., 1997; Herek, 1990; Herek & Glunt, 1988). The results of this study did not provide evidence for many negatives in non-disclosure. In fact for many non-disclosure or rather very limited disclosure, appeared to be a way of coping with the virus and avoiding negative outcomes. By keeping it a secret many seemed to find some way to fight the virus and remain positive. Non-

disclosure provided comfort for some as they did not have to fight stigma and discrimination, instead they could get well independently and return to the world untarnished, as illustrated in extracts 8 and 9.

Holt et al., (1998) described disclosure for gay men as a coping mechanism as it reduces tension and provides opportunities for support, sharing of responsibilities, etc. Although it should be noted that in this study only one participant is homosexual his experience of disclosure should be included. In this case disclosure may have been done to fulfill the need of support from someone within the same community and releasing tension. As shown in extract 5, the reason for disclosure seemed to go beyond just support and tension releasing, disclosure occurred because the participant felt safe to do so, based on what he heard from the gay community. Further, Levy et al., (1999) state that disclosure is a reflection of how a person is experiencing and coping with HIV. It seems for this participant he may be experiencing HIV as something that should remain secret from those who are not apart of the infected community. He appears to cope with HIV by remaining within this community and thus keeping his status secret.

The theme of disclosure, referring to the decision to tell or not tell as well as to whom one should disclose, appeared to be very reflective of subjects' strategy for survival. For some subjects non-disclosure or secretivity seemed to empower them because they did not have to face the stigma and discrimination they perceived. Instead they were able to select a few individuals to disclose to, as shown in extracts 2 – 4, and fight the virus privately, while keeping up a healthy, false image for the public. On the contrary, participant 2 used public disclosure as a way of coping with the virus. As shown by extract 6, he used public disclosure to fight HIV as it helped him shift his focus from the negative consequences of his infection to more positive ones, such as educating others. As described by de Bruyn (1998), participant 2's disclosure led to him adopting the role of educator. Further, public disclosure seemed to foster good relations

with others as well as provide numerous opportunities for support. These findings correlate with those reported by Paxton (2001) and FXB center (1997).

## **2.2. Stigma**

Stigma, to a large extent, seems to inform peoples' strategies for survival. Although people expressed fear of experiencing stigma, as seen in extracts 11 – 13, none mentioned experiencing it in reality, with the exception of participant 2. This appears to be consistent with the literature that describes two types of stigma; enacted and felt (de Bruyn, 1998). De Bruyn (1998) refers to felt stigma as that which HIV positive people have not experienced, but perceive to exist and enacted stigma as that which has actually been experienced.

Stigma represents the voice of society and Stewart et al. (2002) view stigma as a social process. Stigma seems to disempower HIV positive people in that they feel the need to keep their illness a secret and would often shoulder the burden alone, rather than share their diagnosis. It is found in all areas of existence, including employment. Some studies have shown how stigma in the workplace prevents disclosure (Kinniburg et al., 2001 & Sinkoyi, 2000). de Bruyn, (1998) found that stigma seems to change the way in which people see themselves. Most participants in this study appear to judge themselves through the eyes of the stigmas associated with HIV and did not attempt to fight against it, instead they only disclosed to one or two people and used medication to hide the fact that they were ill, as shown in extract 31.

It seems that stigma prevents people from accepting their diagnosis. If they accepted their diagnosis they would have to examine the accusations brought along with stigma and actively fight to prove society wrong. Instead people seem to choose to see themselves as being infected by something from which they can recover. Thus it seems that people's fear of stigma forces them to put on a charade not only for the public, but for themselves too.

### 2.3. Denial

The theme of denial forms a major part of the experiences of HIV positive people. Research has shown that denial may result from a lack of social support and fear of stigma (AIDS Alert, 2001). This strategy for survival or coping style appears to allow people to cope with their positive status by accepting certain aspects of the illness and denying others. It also allows participants to avoid disclosure, as they are able to create an illusion of recovery for themselves, as shown by extract 16. In this way they are able to deny the need for support from others and avoid facing stigma that might result from disclosure.

Some participants tended to show denial through the use of defense mechanisms, such as minimizing, intellectualizing, justification, and rationalization, as seen in extract 15. By using these defense mechanisms participants create a more treatable, manageable virus where the focus is on the physical symptoms and not other consequences, such as emotional pain or death. This seems to fit one of the coping styles described by Grant and Anns (1988, as cited in Moore et al., 1996), where people become neurotic or obsessive about their life and lead a symptom-oriented lifestyle. Thus, through the use of this coping style people are somehow able to avoid thinking of the emotional and more serious consequences of HIV.

The majority of literature concerning denial referred to denial as a reaction to initial diagnosis. However, a study of Kenyan women (Neuvians, 1988) described denial as being expressed in different forms, such as attributing symptoms to other illnesses or sorcery or using the preconceived ideas of what HIV positive people look like in order to deny their own infection. Some participants in this study did focus on this state of physical appearance as a way of denying responsibility and seriousness of the illness, for example extracts 17 & 18.

Denial is just one of the ways in which participants attempt to survive the experience of HIV. It seems to provide a way of reducing the serious consequences of HIV into something that participants can manage on a daily basis.

#### **2.4. Physical symptoms**

The theme of physical symptoms again appears to illustrate the coping style described by Grant and Anns (1988, cited in Moore et al., 1996). People tend to focus on physical symptoms and lead a lifestyle orientated in this direction. It seems that physical symptoms offer a distraction from the emotional “baggage” accompanying an HIV positive diagnosis, as shown by extracts 19 -21. This theme appears to allow HIV positive people to position themselves in society as sick people on the mend, rather than people who are suffering and dying, as seen in extract 18. Somehow physical symptoms provide hope, because the power of medication as well as the knowledge of medical professionals can provide ways of dealing with these symptoms, as shown by extracts 31 and 32. Ezzy and de Visser’s (2000) study support this, as they found people had positive feelings about drugs because it gave them hope. Further, physical symptoms can be fought against physically; people are able to take pills or rub ointment onto their bodies. The theme of physical symptoms provides a way for HIV positive people to receive help and sympathy, without disclosing their status.

Therefore adopting a coping style which focuses on physical symptoms appears to provide relief as many illness associated with HIV are socially acceptable and thus do not have to be kept secret. Physical symptoms allow for treatment through medication and medical professionals, thus fostering hope for survival. It seems this coping style therefore allows for a denial of emotional pain, an opportunity for some social support, as these illnesses do not have to remain a secret, and provides hope for recovery.

## **2.5. Symbolic representations of HIV/AIDS**

This theme, as presented in the results section, was not found in any literature available to me. However, it seems to warrant some discussion as it is presented powerfully in extracts 25 - 28. By identifying the virus in a metaphorical way, HIV positive people are almost able to separate the viruses from themselves. This "space" appears to generate some power as it makes the virus more than just a positive test result, but something alive that one can fight against. One cannot bargain with laboratory results, but one can bargain with something identifiable, such as a living enemy. It is against this defined enemy that HIV positive people are able to create their strategies for survival. Their perception of their enemy seems to determine how they are going to use options, or themes found in this study, available to them, such as disclosure, medication, denial, etc. For example, participant 2 used public disclosure and education as he felt he could 'frustrate' the virus by exposing his HIV positive status to the public. Therefore he seemed to view HIV as something that survives on secrecy.

The way in which this study's participants viewed themselves and the virus appeared to dictate how they were going to respond to the various themes, as it formed their strategy for survival.

## **2.6. Medication**

The literature found reviewing medication specifically does not reflect all of the findings generated under this theme, particularly the power medical professionals seem to have over HIV positive people. Most of the reviewed literature focuses on the side effects and the difficulties involved in taking medication (Golin et al., 2002; Garcia, 2001; Catz, McClure, Jones, & Brantley, 1999). Participants in this study did not focus on the side effects. Most saw medication as a way of preventing their status from becoming known due to repeated illnesses, and as a means of hope to continue living a normal life as shown by extracts 29 and 30.

Ezzy and de Visser's (2000) study support this finding that medication provides hope. Only one participant briefly mentioned side effects, as seen in extract 32. It seems that for some medication was a powerful means of helping them keep their survival strategies in place, especially those who decided not to disclose and fight the illness privately. Medication helps to relieve physical symptoms, which in turn allow the individual to appear healthy, and thus prevents a real acceptance of the total consequences of HIV/AIDS. Thus medication allows for denial of the seriousness of the virus and hides it from society.

While medication may help people live their lives in a particular way, it seems this may expose them to further disempowerment. Once HIV positive people enter the world of medication it seems that they often become captives of the medical world and lose some say over themselves. Their lives appear to become dependent on the opinions of medical professionals as well as test results, as illustrated by extracts 33 and 34.

Medication appears to be both positive and negative in the lives of HIV positive people, as it allows them to not disclose and avoid stigma, but it prevents them from accepting their positive diagnosis fully and may create a 'pseudo hope' for survival.

## **2.7. Depression**

The review of literature showed the prevalence of depression to vary from study to study (Aids Alliance, 2003). As shown in chapter 4, depression seemed to be evident in the majority of the stories, although not always expressed in ways described by classification systems such as the DSM.

Moore et al (1996) describe short-term and long-term depression. They describe short-term depression as a reactive depression. Only one participant spoke about how he felt when first receiving his diagnosis and his depression seems to

reflect the findings of Moore et al. (1996). Following his diagnosis this participant became suicidal and was sent for observation at a mental hospital. Other participants, who were aware of their status for lengthier periods of time, seemed to suffer from long-term depression, as described by Moore et al. (1996).

Participants appeared to express their depression in different ways, as shown by extracts 36 – 39. Some studies, for example, have shown that people who engage in risky behaviors such as unprotected sex are more likely to suffer from depression (Valente, 2003; Kalichman, 2002; Angelino, 2002). Some male subjects' stories did not clearly indicate experiences of depression, but they did admit to engaging or the desire to engage in risky behaviors, as illustrated by the following examples:

'I think I will live a long time. It doesn't matter whether I use condoms or not because I have Aids if other people don't want it they should not sleep around' (Participant 5); 'Besides, if I intended on living my life it wouldn't have been the last time I took risks' (Participant 1).

From the existing literature, (Valente, 2003; Kalichman, 2002; Angelino, 2002), and above examples it seems that while these subjects may not have verbalized their depression as clearly as others, they may be at risk for depression.

It is interesting that Valente (2003) states that depression is frequently unrecognized, however from the stories it seems that most participants in this study did not verbalize feelings normally associated with depression or symptoms described in the DSM IV. Depression was identified from descriptions of the body, as seen in extracts 38 and 39, and through risk taking behaviours. Only participants 2 and 6 verbalized feelings and thoughts, in extract 36 and 37, that may lead to a diagnosis of depression as described by the DSM IV. Participants seemed to put on a positive face and avoided expressing feelings of sadness. Perhaps depression is largely unrecognized because it does not always

reveal itself in the expected or classified way. Notman (1989, as cited in Rapmund & Moore, 2000) found that depression in women is often manifested through physical complaints. Rapmund and Moore (2000) expand on this view, they go on to state that physical symptoms often mask depression as women's mental health problems are often minimized by doctors, and in turn by women themselves so that these problems are largely ignored. Women find an alternative way of expressing their mental problems through a more acceptable means. Two of the female subjects in this study expressed their depression by describing their physical symptoms. It appears that while women tend to express depression through their bodies, men may express it in their own way, such as through risk taking behaviours.

It seems that HIV positive people can talk about their physical symptoms because they are often representative of illnesses experienced by HIV negative people too, for example:

'My mother knows I am sick but thinks I have T.B' (Participant 4).

Therefore, HIV positive people are able to minimize their illness for themselves and hide it from others by focusing on their physical symptoms only as their HIV positive status cannot be identified from these physical symptoms, making it a "safe topic" for public discussion. It seems that emotional pain, such as depression, is hidden from others and even the self, through the use of defense strategies, such as minimization, since if it were to be revealed together with physical symptoms then the seriousness of the person's condition may be realized and the question of an HIV positive status may be raised.

Depression appears to be part of most HIV positive peoples' experiences, however it may not always be observable through the use of the usual classification systems, such as the DSM IV.

## **2.8. Anger**

As described in chapter 4, this theme represents anger towards the source of infection (blame), revenge, as well as feelings of helplessness and disempowerment, as shown by extracts 41 - 43. Supporting this theme, Grant and Anns (1988, as cited in Moore et al, 1996) do mention that some HIV positive people remain angry and follow self-destructive paths.

The existing, reviewed literature focuses mainly on anger after initial HIV positive diagnosis (Andrews et al., 1995; Moore et al., 1996; Paxton, 2001; Coleman, 2003). Neuvians' (1988) study of Kenyan women described as anger one of the responses to an HIV positive diagnosis. They found that some women blamed their partners for their infection. In this study both genders directed their anger at their source of infection, as illustrated by extracts 41 and 42. Grant and Anns (1988, as cited in Moore et al, 1996) and Ross et al. (1989, as cited in Moore et al, 1996), described anger as a common reaction to an HIV positive diagnosis. This appears to hold true in this study as half of the participants showed anger, as shown in the table of themes in chapter 4.

## **2.9. Death**

The theme of death appears to represent the dilemmas facing HIV positive people and highlights the strategies they use to survive. It seems that many of the other themes are used to avoid really thinking about early death caused by AIDS related illnesses. An example of this may be seen in extract 45. A study of Kenyan women's reactions to an HIV positive diagnosis found that many women try to minimize the consequences of the effects of HIV by saying that everyone is going to die anyway (Neuvians, 1988). Participants in this study tended to use similar strategies to deal with death, for example, some used physical symptoms and medication to minimize the seriousness of the virus and avoid feelings or

discussing emotional pain, such as depression. It seems that many participants positioned themselves in a positive frame of mind to prevent themselves from dwelling on feelings of fear and sadness related to the ultimate consequence of an HIV positive diagnosis; death.

Medication appeared to provide some sort of buffer against facing death. Many used hope of a prolonged life to put off thinking beyond the possibility of death. Despite this hope, at some point most participants did express ambivalent feelings as to whether they would really be able to beat the virus or not. However, these doubts were often replaced by descriptions of strategies for fighting the virus, as seen in extracts 44-46.

Thus, it seems that although subjects are aware of the consequence of death associated with HIV/AIDS, they use other themes, such as denial and physical symptoms, to avoid facing death. A positive, public face is put forward to deny the virus as well as death or at least to minimize it into something more normal that one can fight and perhaps beat.

### **3. Summary of the discussion**

It seems that while the experience of living with HIV may differ for each individual there are some commonalities, such as the following main themes: disclosure, denial, stigma, physical symptoms, symbolic representations of HIV/AIDS, medication, depression, anger, and death. While many similarities were found between this study and the reviewed, existing literature, some differences emerged. In addition, some findings, such as symbolic representations of HIV/AIDS, were not available in existing literature and had to be discussed in the light of the results only.

Perhaps the most striking feature found in all experiences is the way in which each individual seemed to find a way of coping or a strategy for survival. Strategies for survival were not discussed as a theme, as they materialized from the themes, but were discussed under relevant themes. These survival strategies appeared to be in response to each participants' symbolic representation of HIV/AIDS. In addition to symbolic representations of HIV/AIDS, the theme that greatly influenced these strategies for survival was stigma. Stigma created fear for many participants and thus often influenced them into adapting a survival strategy that would allow a private fight, with very limited amount of disclosure.

#### **4. Implications**

The findings of this study show that stigma is a powerful shaping agent in the lives of HIV positive people. The majority of participants did not disclose due to fears of stigma. Thus it is an area that needs addressing by further research and HIV/AIDS campaigns.

Strategies for survival that emerged from the various themes appeared to reflect how participants experienced the virus and may be useful in identifying needs of HIV positive people and directions for future HIV/AIDS campaigns.

Medication and the medical profession seem to provide a symptom-focused approach to HIV, which appears to ignore the emotional aspects of the virus. Perhaps future HIV/AIDS campaigns need to focus more on the emotional needs of HIV positive people to provide a balanced view of what it is like to live with the virus and what HIV positive people need from their families, friends, and medical practitioners. Further, a "pseudo hope" for survival seems to be associated with medication and therefore it seems that education is needed around medication in order to prevent "pseudo hopes" and further emotional distress resulting from disappointment.

Depression was found in some stories, but did not always present in the ways described by classification systems, such as the DSM IV. Future research may be necessary to explore the expressions of depression found in this study and to educate medical professionals about these findings.

## **5. Limitations of this study**

Literature was not always available to validate findings of this study and thus findings had to be discussed on their own. Therefore, these findings may be worthy of future research. In addition, it may be worthwhile to conduct a quantitative study in this area to verify findings further.

Caution is advised when generalizing findings from this study, as the sample used is very small and did not include all South African race groups. Future research needs to explore a larger and more diverse sample in order to increase generalizability, and to perhaps satisfy other research methodologies.

While all attempts were made to bracket out any biases, it is not possible to ensure this was achieved completely. Therefore, my biases may have coloured findings to some extent.

## **6. Conclusion**

The findings of this study seem to highlight a need for further research into the actual experience of living with HIV/AIDS in order to fight stigma and understand not only the physical experience of the virus, but also the emotional. Hopefully by gaining further understanding into emotional issues, campaigns may be designed to educate people, both HIV positive and negative, around these issues and medical professionals may be informed on how to improve services for their HIV positive clients.

## References

- AIDS Alert, (2001). Fear of disclosure and popular stigmas contribute to bad outcomes. AIDS Alert, 16(2), 13-17.
- Aids Bulletin, (2001). Domestic Workers And Aids Discrimination. Aids Bulletin [Online], 10(3), 2 pages. Available: <http://www.allAfrica.com> [2003, March 19].
- Aids Alliance, (2003). Depression in HIV positive people [Online]. Available: <http://www.aidsalliance.org> [2003, March 15].
- Andrews, L.J. & Novick, L.B. (1995). HIV care A comprehensive handbook for providers of health care. U.K.: SAGE Publishers.
- Angelino, A.F. (2002, August). Depression and adjustment disorder in patients with HIV disease. Paper presented at the Clinical Pathway of the Ryan White CARE act 2002 all grantee conference, Washington, DC.
- American Psychiatric Association. (2000). Diagnostic and statistical manual of mental disorders (4<sup>th</sup> ed.), Text Revised (DSM-IV-TR). Washington, DC: Author.
- Ashworth, P. (1996). Presuppose nothing! The suspension of assumptions in phenomenological psychology method. Journal of Phenomenological Psychology, 27(1), 2-23.
- Carovano, (1995). HIV and the challenges facing men [Online]. Available: <http://www.undp.org> [2003, April 30].

- Catz, S.L., McClure, J.B., Jones, G.N., & Brantley, P.J. (1999). Predictors of outpatient medical appointment attendance among persons with HIV. AIDS Care, 11(3), 361-373.
- Chadwick, (no initials available). (2003). Disclosure of HIV/AIDS [Online]. Available: <http://www.positivevisionuk.org.uk> [2003, April 5].
- Chirila, O., Petrea, S., Cotoanta, I., & Voicu, I. (2002, July). The opportunity of disclosure and the process of telling to HIV children and adolescents. In AIDS 2002 XIV International AIDS Conference, Barcelona [Online]. Available: <http://www.aids2002.com> [2003, April 3].
- Coleman, B. (2003). Counselling recently diagnosed persons with HIV [Online]. Available: [http://www.cpa.ca/PHASE/Recent\\_diagnosis](http://www.cpa.ca/PHASE/Recent_diagnosis) [2003, June 12].
- de Bruyn, T. (1998). HIV/AIDS and Discrimination: a discussion paper. Canadian Montreal: HIV/ADS Legal Network and Canadian AIDS Society.
- Durrheim, K. (1997). Social constructionism, discourse, and psychology. South African Journal of Psychology, 27(3), 175-181.
- Dugan, V.; Agalar, F.; & Sagek, I. (2001). Surgeons' attitudes towards HIV/AIDS in Turkey. AIDS Care, 13(2), 243-251.
- Ezzy, D. & de Visser, R. (2000). HIV futures: The social aspects of living with HIV/AIDS in South Australia. Australia: South Australian Health Commission.
- Fan, H., Connor, R.F., & Villarrea, L.P. (1989). Biology of AIDS. Boston: Jones & Bartlett Publishers.

- Forehand, R., Armistead, L., Mose, E., Simon, P., & Clark, L. (2003). The Family Health Project: An Investigation of Children Whose Mothers are HIV-Infected [Online]. Available: <http://www.fcny.org> [2003, April 30].
- Fesko, S.L. (2000). Disclosure of HIV status in the workplace: Considerations and strategies. Health and Social Work, 42, 523-549.
- Fesko, S.L. (a: 2001). Disclosure of HIV status in the workplace. Health and Social Work, 26(24), 235-278.
- Fesko, S.L. (b: 2001). Workplace experiences of individuals who are HIV positive and individuals with cancer. Rehabilitation Counseling Bulletin, 45(1), 2-16.
- FXB Centre, (1997). Reactions to disclosure [Online]. Available: <http://www.fxbcentre.org> [2003, April 3].
- Garcia, A. (2001). Women, HIV, and Depression [Online]. Available: <http://www.projectinform.org> [2003 February, 18].
- Giorgi, A. (1994). A phenomenological perspective on certain qualitative research methods. Journal of Phenomenological Psychology, 25, 190-220
- Golin, C., Isasi, F., Bontempi, J.B., Eng, E. (2002). Secret pills: HIV-positive patients' experiences taking antiretroviral therapy in North Carolina. AIDS Education, 14(4), 318-329.
- Green, J. & McCreamer, A. (1992). Counseling in HIV infection and AIDS. London: Blackwell Science Publishers.

- Hall, S.K. (2001). Attitudes of young adolescents towards HIV/AIDS. Unpublished honour's thesis, University of Zululand, Zululand.
- Hankins, C. (1996). Human rights, Women, and HIV. Canadian HIV/AIDS Policy & Law Newsletter, 2(4).
- Herek, G.M. & Glunt, E.K. (1988). An epidemic of stigma: public reactions to AIDS. American Psychologist, 43(11), 888-891.
- Herek, G.M. (1990). Illness, Stigma, & Aids. In P. Costa & G.R. Vanden Bos (Eds.), Psychological aspects of serious illness. (pp. 105 – 150). Washington, DC: American Psychological Association.
- Herek, G.M. & Glunt, E.K. (1991). AIDS-related attitudes in the USA: a preliminary conceptualization. Journal of Sex Research, 28(1), 99 -120.
- Hodgson, I. (1999). Myth and HIV: the role of cultural narrative in the construction of HIV/AIDS [Online]. Available: <http://www.brad.ac.uk>. [2001, March 3].
- Holt, R., Court, P., Vedhara, K., Nott, K.H., Holmes, J., & Snow, M.H. (1998). The role of disclosure in coping with HIV infection. In AIDS Care, 10(1) [Online]. Available: <http://www.aegis.com/pubs/aidsline> [2003, April 30].
- Issiaka, S., Cartoux, M., Ky-Zerbo, O., Tiendrebeogo, S., Meda, N., Van De Perre, P., & Dabis, F. (2001). Living with HIV: women's experience in Burkina Faso, West Africa. AIDS Care, 13(1), 123-129.
- Kalichman, S.C. (2002). Continued unsafe sex practices among HIV seropositive persons: implications for intervention. Washington, DC: American Psychological Association.

- Karasic, D.H. & Dilley, J.W. (1998). HIV-associated psychiatric disorders [Online]. Available: <http://www.hivinsite.org> [2003, April 10].
- Key, S.W., DeNoon, D.J., & Boyles, S. (1998). Men with HIV less likely to tell partners. AIDS Weekly Plus, 3/2/98, 18-19.
- Key, S.W. & DeNoon, D.J. (1997). HIV positive employees may face continuing workplace discrimination. AIDS Weekly Plus, 11/10/97, 27-28.
- Khoransee, J. (2001). Overlooked populations and HIV prevention [Online]. Available: <http://www.thebody.com> [2003, April 6].
- Kinniburg, J., Scott, P., Gottlieb, M., & Power, L. (2001). Prejudice, Discrimination and HIV-a report. England: Terrence Higgins Trust.
- Kruger, D. (1979). An introduction to phenomenological psychology. Cape town: Juta and co. ltd.
- Leask, C., Bor, R., Eford, J., Miller, R., & Johnson, M. (1997). Selective disclosure: a pilot investigation into changes in family relationships since HIV diagnosis. Journal of Family Therapy, 19(1), 59-69.
- Leedy, P.D. (1997). Practical Research Planning. (6<sup>th</sup> ed.) New Jersey, USA: Prentice Hall.
- Levy, A.; Laska, F.; Abelhauser, A.; Delfraissy, J.; Goujard, C.; Boue, F.; & Dormont, J. (1999). Disclosure of HIV seropositivity. Journal of Clinical Psychology, 55(9), 1041-1049.

- Lindegger, G. & Wood, G. (1994). The AIDS crisis: review of psychological issues and implications, with special reference to the South African situation. South African Journal of Psychology, 25(1), 1-10.
- Lynch, A. (1989). AIDS-related suffering: Therapy, healing, or ? In Hallman, D.G. (Ed.), AIDS Issues: Confronting the challenge, (pp.121-141). New York: The Pilgram Press.
- Maman, S., Mbwambo, J., Hogan, M., Kilonzo, G., Sweat, M., & Weiss, E. (2001). Implications for HIV voluntary counseling and testing programs in Dar es Salaam, Tanzania. (Horizons project report.) Washington, DC: Population Council.
- Miles, M.B. & Huberman, A.M. (1994). Qualitative data analysis: an expanded sourcebook. Thousand Oaks: Sage.
- Moore, S., Rosenthal, D., & Mitchell, A. (1996). Youth, AIDS, and STDs. London: Routledge
- Neuvians, D. (1988). HIV/AIDS within the family: women's responses and needs [Online]. Available: <http://www.hivinsite.org> [2003, March 15].
- Parker, k. (1992). Discourse dynamics. Critical analysis for social and individual psychology. London: Routledge.
- Paxton, S. (2001). Public disclosure of serostatus – the impact on HIV-positive people [Online]. Available: <http://www.kit.nl/information-services/exchange-co1-public-disclosure-of-se.as> [2003, April 30].

- Polkinghorne, D.K. (1989). Phenomenological research methods. In Vaill, R.S. & Halling, S. (Eds.). Existential-phenomenological perspectives in psychology. (pp.41-60). New York: Pleaum Press.
- Rapmund, V., & Moore, C. (2000). Women's stories of depression: a constructivist approach. South African Journal of Psychology, 30(2), 20-29.
- Schrimshaw, W. & Siegel, K. (2002). HIV-infected mothers' disclosure to their uninfected children: rates, reasons, and reactions. Journal of social and personal relationships [Online], 19(1), 1 paragraph. Available: <http://www.sagepub.co.uk/journals>.
- Serovich, J.M. (2001). The role of family and friend social support in reducing emotional distress among HIV positive women. AIDS Care, 13(3), 335-342.
- Shell, R., Quatteck, k., Schonteich, M., & Mills, G. (2000). HIV/AIDs: a threat to the African Renaissance? South Africa: Konrad-Adenauer-Stiftung.
- Siegel, K., Karus, D., & Schrimshaw, E.W. (2000). Racial differences in attitudes towards protease inhibitors among older HIV-infected men. AIDS Care, 12, (4), 423-437.
- Simoni, J.M., Mason, H.R., & Marks, G. (2002). Disclosing HIV status and sexual orientation to employers [Online]. Available E-mail: [jms112@columbia.edu](mailto:jms112@columbia.edu) [2003, March 30].
- Sinkoyi, S.T. (2000). The subjective experiences of people living with HIV and how these impact on their quality of life. Pietermaritzburg: University of Natal.

- Sprig, (2002). In invisibility and isolation: the experience of HIV-affected families in German speaking Switzerland. Qualitative Health Research, 12(10), 1323-1337.
- Stewart, R., Pulerwitz, J., & Esu-Williams, E. (2002). Addressing HIV/AIDS stigma and discrimination in a workplace program: emerging findings [Online]. Available: <http://www.archives.healthdev.net/af-aids> [2003, March 10].
- Stones, C.R. (1986). Phenomenological praxis: a constructive alternative in research psychology. South Africa Journal of Psychology, 16(4), 117-121.
- Strebel, A. (1995). Whose epidemic is it? Reviewing the literature on women and AIDS. South Africa Journal of Psychology, 25(1), 12-18.
- Terre Blanche, M.T. & Kelly, K. (1999). Interpretive methods. In Durrheim, K. & Terre Blanche, M. (1999). (Eds.), Research in practice: applied methods for the social sciences. (pp.123-146). Cape Town: University of Cape Town Press.
- Travers, R. & Paoletti, D. (1999). Responding to the support needs of HIV positive lesbian, gay, and bisexual youth. Canadian Journal of Human Sexuality, 8(4), 271-285.
- Trujillo, L., O'Brien, M.E., Kendall, C., Hassig, S., Volle, J., & Kissinger, P. (2001). Factors associated with HIV disclosure to family and friends [Online]. Available: [www.ncbi.nlm.nih.gov/entrez](http://www.ncbi.nlm.nih.gov/entrez) [2003, April 30].

UNAIDS, (2002). AIDS epidemic update [Online]. Available:  
<http://www.unaids.or> [2003, April 30].

University of Pittsburgh Medical Center, (2003). (Untitled) [Online]. Available:  
<http://aids.upmc.com/Diagnosis.htm> [2003, April 30].

Valente, S.M. (2003). Depression and HIV disease. Journal of Associated Nurses AIDS Care, 14(2), 41-51

Van Dyk, A. (2001). HIV/AIDS care and counseling: a multidisciplinary approach. Cape Town: Pierson Education.

Vest, J.M., Vest, M.J., Perry, S.J., & O'Brien, F.P. (1995). Factors influencing managerial disclosure of AIDS health information to coworkers. Journal of Applied Social Psychology, 25, 1043-1057.

Wicks, L.A. (1997). Psychotherapy and AIDS: the human dimension. USA: Taylor & Francis.

Zagumny, M.J. & Deckbar, R. (1995). Willingness to work with and sympathy for HIV-positive coworkers: an experimental examination of mode transmission, concern, and knowledge. Psychological Reports, 77(2), 571-588.

## **Appendix A - Participants' stories**

### **Participant 1 (White, homosexual male):**

#### **I HAVE AIDS, BUT WILL IT KILL ME?**

(A personal journey)

I remember the first time I met somebody who told me he was HIV+. It was more than ten years ago when I travelled overseas for a year. I was 25 at the time and stayed in London for a few months during my travels. That was also the year I finally came out of the closet. After I had seen a bit more of the world and the people that live in it, I ceased my tiring attempts at being straight. I'd had enough of trying to live somebody else's life. I was staying with Martin in London when he told me he was HIV+. We had a fling the year before in Cape Town when he was on holiday in South Africa and I contacted him when I arrived in England about six months later. He was my first real fling with a man (excluding a few guilty hit and run one-night-stands when I was a student). The affair lasted the two weeks of his stay in Cape Town.

My reaction to Martin's revelation could've been fear and hatred, considering he didn't tell me before the affair, but that's not what I felt. I felt that if he could have a deadly disease and still look that healthy and sexy, I wouldn't mind having it with him. I always believed more in my inner voice than I did the newspapers or any scientific studies. Besides, if I intended on living my life it wouldn't have been the last time I took risks. I was also quite sure that Martin didn't infect me. He was so intent on playing it safe when we were together that I actually became irritated with all the precautionary measures. On my way to England I also had a compulsory HIV test on the kibbutz. I never received the result of that test, but assumed that I would've been kicked off the kibbutz if the results had been positive.

By the time I arrived in London Martin had met Chris at a get-together for HIV+ people and they became involved. Apart from Chris, I then also met some of Martin's other friends who were all HIV+. They invited me to parties where the majority of the guys were HIV+. Although these men were all very aware of their HIV status, they all seemed healthy to me. His one friend, about the same age as me, once showed me the sores on the insides of his thighs. To me it looked like heat rash that got infected from scratching. London had a heat wave that summer and it was very hot, even for a South African like myself. He told me his doctor diagnosed the sores as an opportunistic infection caused by HIV. None of Martin's HIV+ friends expected to live very long and they were conscious of the fact that life is now and one should make the most of the moment. I didn't think it was a bad philosophy, but a hard one to follow if you're used to living in hope of a better life like I did. They also had weekends away where their disease and the imminence of death were discussed. Martin had a more positive outlook and used Chris' case as an example that one can live longer with HIV than the expected two or three years people were talking about then. Chris had been diagnosed with HIV five years earlier and was still healthy.

I lost contact with Martin and his friends when I came back to South Africa. I don't know if some of them did become seriously ill and died eventually or how many of them became 'long term survivors'. My doctor who specialises in Aids tells me that most of his overseas friends who contracted Aids in the eighties have since died. Until about five years ago I had never heard of any of my South African friends or acquaintances that were HIV+. I know of two gay men that I've personally met who have died of Aids in the last few years, but I didn't know much about their personal circumstances. Even though most of my friends are gay, none of my personal friends or any other acquaintances in the two South African cities where I have lived for the last ten years have died of Aids or even been seriously ill. In the last five years however, I have heard more and more about guys that I personally know who apparently are HIV+. They didn't tell me this themselves, but I know a number of people in the gay community who can't

keep a good story to themselves. None of these men have since become seriously ill or died. When I was diagnosed with Aids a few months ago, I confided my status to a very close friend. He was one of the friends that through the grapevine I suspected of being HIV+. I never had the guts to ask him about his status before and I don't think he really discussed his status with any of his friends. But when I told him about myself, he told me that he tested positive eleven years ago. At that stage nobody spoke about it in this country.

I only went for an Aids test when I started getting ill last year. I wonder how many of my acquaintances are HIV+ and don't know this because they are scared to go for a test, and how many more know they are positive, but wouldn't tell me just like I wouldn't tell them.

For various reasons my doctor believes that I've probably had the virus for about ten years. There must be many like my friend and I who can be considered 'long term survivors'. The current belief is that people with HIV or Aids can be kept alive with anti-retroviral drugs. Apparently these drugs only really started making a difference in the last five years. My question is - how did we all survive until now and why were Martin and his friends not dying or at least some of them becoming seriously ill when I knew them more than ten years ago?

I have no doubt that I have Aids. All the symptoms I had last year were Aids related. I also know that many people who had these symptoms and related diseases have died from this. On the other hand if I look at the number of people in the Western world who have died of Aids in the last twenty years and the number of people currently HIV+, I come up with a very small minority of the infected pool who have actually died. [In Sub-Saharan Africa the situation looks very different, but there millions of people don't even have running water or proper nutrition. How can they be expected to survive?] I know the argument is that the majority of HIV infections only took place in the last few years and that the future predictions for Aids deaths therefore look catastrophic.

5 This is where the confusion between the time of infection and the time of testing comes in. Just because far more people go for HIV tests now than five years ago doesn't mean they only became infected in the last five years. No, they only went for a test in the last five years! They might have been infected for ten years or more without knowing it, like my doctor believes happened in my case. Not all HIV+ people get Aids (nobody knows what percentage of people will always just stay carriers and never become ill themselves) and it's impossible to tell how long the majority of HIV+ people have been positive. It is hard to believe future predictions about Aids. Not one of the estimates of Aids deaths that were made for the Western world in the last twenty years even came close to the catastrophic numbers that were predicted.

The other day I went to see my doctor about the advisability of continuing with anti-retroviral therapy since I'm not sick anymore. I started taking them when I was diagnosed with Aids last year. I feel very healthy at the moment, but get unpleasant side effects from the chemical anti-retrovirals. I'm also very worried about the long-term effects of taking these toxic drugs for a prolonged period. My doctor was very strongly opposed to the idea of stopping the medication. Even though I feel and look very healthy my doctor made it clear that I will not live long if I stopped taking the medication. Apparently the drugs are 'buying me time' and without it I will gradually die a horrible death. He said it would only be a matter of time. Needless to say, the healthy man that entered the doctor's room that day, felt like a very sick man when he left.

Who am I to challenge a doctor who specialises in this condition? What do I know about my own body? This syndrome was identified and proven under a microscope and the signs your body gives you can't be relied on anymore. Science is almighty and the human body knows nothing. Only a medical doctor can tell you when you will live and when you will die. Who has the guts to take

his life in his own hands by discontinuing anti-retroviral therapy when the doctor is absolutely sure that you will die? Not me!

I recently met Greg. He was diagnosed HIV+ twenty years ago and lived a healthy life for seventeen years before he became ill. He has been on anti-retrovirals for the last three years. He believes he went through a very difficult phase in his life three years ago and that played a major role in him becoming ill. Its interesting that I also experienced hardship and failure in the most important sectors of my life at the time when I became ill. Mentally and emotionally my life basically came to an end at the time. That period is over now and I'm sure anti-retroviral therapy as well as antibiotics played a major role in helping me get through it on a physical level. But is it really true that I'm dependent on medication for the rest of my life? Or is that just something the medical profession believes? In addition to anti-retrovirals I've been on antibiotics for almost a year. My low cd4 count warrants the daily dose of antibiotics.

Sometimes it feels like this disease has nothing to do with the actual state of your health, but more what lab tests, cd4 counts and viral loads tell the doctor. With all the science and medical tests available to analyze the body, the medical profession has somehow forgotten to look at the actual person.

I believe Aids is far more complex than HIV = Aids. It's foolish to take this tiny aspect of the disease and turn it into the major defining factor like the media and the medical profession have done over the last twenty years. It is clear to me that the medical profession understands only the physical part of a human being. They know very little about the impact the human psyche has on our physical well being. When you talk about the cause of diseases, they point to viruses and bacteria. Instead of fighting these micro organisms we should be looking at ourselves. What causes one person to be immune or recover from a disease and another not?

Hopefully one day the world will realize Aids is just a symptom of the much vaster disease, namely social decay. Like with many other things, good and bad, this is something that gay men are at the forefront of. By that I don't mean it's socially destructive to be gay. I'm talking about the daily life of the average gay man and how that affects his own well being. But that's a thesis in itself.

I fear the HIV virus as much as I fear the next flu virus. I have a much greater fear for social isolation and a lack of care from my fellow human beings, because I know that can kill me.

**Participant 2 (Zulu, heterosexual male):**

I was diagnosed early 1992 in Durban at Addington Hospital. I firstly felt very ill I had an unstoppable running stomach, headache, sweating, lost of appetite and felt very tired. One morning I decided to go to Hospital and seek for treatment. Fortunately the Doctor knew about the symptoms of HIV/ AIDS. He asked me if I was free to go for the blood test and agreed to be tested. At time I had never received any counseling from the doctor. I was told to come back after 2 weeks to get the results. I never told my girlfriend I went for test. I went again to hospital to get the results and the doctor told me I am HIV positive and there is no cure for AIDS so I can go home. And again I didn't get a counseling. When I arrived at home I didn't know what to do that is when I planned to commit suicide. But I ended up in hospital where I was observed for a mental disorder. After 3 weeks in hospital the doctors sent me to the ARK CHRISTIAN MINISTRIES, because I could not accept my HIV positive status. When arrived the Pastors in the church explained to me that HIV is a normal disease like any other disease. While I was at the they made me to attend church service and Bible study classes. That is when I experienced the power of God. I told myself, "My body is a Temple of God and the virus it is in the wrong place, it does not deserve to be here." 1994 I a NGO which is (Napwa) National Association for people with HIV/ADS. That was my first time to disclose my HIV status to the public through Media News papers/

Radio and the Television. In 1997 I went to visit my father who lives in Port Elizabeth and I told him I 've got HIV. Unfortunately he was 79 years old at time, and he does not understand what HIV/AIDS. I explained to him that HIV is a killer disease and he asked if I do take my medication and told me he would pray for me.

My second challenge was to disclose to the mother of my children. She told me straight away that I have to distance myself from her and my children. My children love me and they would always play with me but she didn't like that. I had to sit down with her and educate her about HIV/AIDS. Today she is supporting me and she loves me.

At that stage I realized that if I keep this a secret, it was going to destroy my immune system. I believe that when I talk about it, that it heals I am also frustrating it. I can live longer if I am living a positive life. Because with HIV/AIDS, even though it is in your body, your mind must be liberated. That is reason I decided to disclose my status.

When I called the Radio Talk Show most people wanted to know what made me to take this decision, and I said them Disclosure and acceptance is the healing process.

I went for different HIV/AIDS courses in South Africa and I attended different conferences and seminars around the world. I served in different committees.

I never had any problems with the communities, I've been working as volunteer in different companies, churches, Institutions, Government Hospitals to educate and show the positive face into the epidemic. No one has ever challenged me when I walk in the and those who point fingers at me that doesn't worry me, I know I am what I am, and HIV/AIDS doesn't choose colour, race, age or sex.

My commitment is based on education because I know people in South Africa are beyond HIV/AIDS Awareness.

At the moment I do not take any drug therapy. My believe is that God will bring the even it not now But only for the next generation that is my only prayer to God.

**Participant 3 (Zulu, heterosexual female):**

I am 34 years old and have three children. They are 17 years, 8 years and 4 years. I don't have husband and my boyfriend died last year. My mother knows I have AIDS/HIV but my friends don't. I am going to tell them, maybe. I have been sick for one year. I don't think I am going to die I will get better. I have accepted the sickness; I was counseled at the clinic before I got my results. My mother also told me I must accept it. I don't have many friends that is why they don't know. My boyfriend died, they shot him but before he was killed he had cramps like me. I think he was sick as well. I'm not scared of being ill, but it is hard not working. I used to work but now I can't I can't tell my work because if they think I have this sickness they won't take me back. I will be strong enough to go back to work. My mother and aunty both look after my children. My aunty doesn't know. I feel I can get better I never tell myself I am going to die I go to the Nazareth church I haven't told them I am sick. My big daughter sees that I am not well. I don't really want to tell her what I have. I will tell her soon. My brother knows because he gives money to my mother to help look after the children. I don't feel good. I feel all black inside my kidney's feel heavy and black. I can't hold things my hands don't work properly and I can't work either. I am sure that I will get better. I stay positive because I know I can beat this thing. Next week maybe I will feel better and be able to walk.

**Participant 4 (Zulu, heterosexual female):**

I am a 30 year old teacher, I have not been sick for very long only 6 months. I feel as if I have no life left. My children do not know I have this illness and I am not going to tell them. They are quite young 11 years a girl and 8 years a boy. My mother knows I am sick but thinks I have T.B. My sister, she is a nurse so she

knows what is wrong with me. I do not have a husband only a boyfriend. I have not told him I am sick. He does not look sick but I think he must be. I think he has other girlfriends but I am not sure. I feel like this thing is eating me, I am very weak. I have medicine they told me I can take it from tomorrow. I haven't told the school where I work what is wrong with me. I don't think I am going to tell them unless I have to have too much time off. My friends don't know that I am sick I am not going to tell them. There is too much trouble the people would stone us. I feel heavy inside everything is too heavy. I think that now I have the medicine I won't die. All the nurses tell me to stay positive I just feel very tired. I don't think I will die. My boyfriend doesn't know I am in hospital; I am not going to tell him. The doctor says I can go home soon then I will feel better when I'm at home.

**Participant 5 (White, Afrikaans, heterosexual male):**

I have been on contract here for 2 years. My wife stayed behind in Pretoria. I like contract work because I get to have a lot of freedom. My children are 14 and 12 years old. \*Jack is the eldest; he is good at school and sport. \*Jill is 12 years old; she is like her Mother clever and bossy. I started to feel really tired at the beginning of the year and lost a lot of weight. At first I was pleased because I was getting to fat. I soon started to get scared because I kept losing weight and I got a rash on my skin and my mouth. I had a very bad stomach; you now I kept on running to the toilet. The doctor just thought I had stomach flu but when it wouldn't go away he started asking me some questions. I sometimes go to see the girls at one of the bars and I don't always use condoms. The girls are Chinese, I think so I didn't think they could be sick. The Chinese are very clean. I found out I had Aids I must have got it there. The trouble is I haven't told my wife and I don't use a condom when I sleep with her. I also have another girlfriend here and she doesn't know either. I think that I will live a long time with the drugs they give me. My wife isn't sick, neither is my girlfriend. I know my girlfriend has other boyfriends and I think my wife has as well. I will only tell them when they get sick, they won't know they got it from me I will say I got it from them. I will not tell

my friends or workers that I have Aids they will think I am sleeping with blacks. Anyway I feel better now that I have the drugs nobody can see that I am sick. I think I will live a long time. It doesn't matter whether I use condoms or not because I have Aids if other people don't want it they should not sleep around. I feel strong but angry at the Chinese woman who gave me this illness, she deserves to die.

\* Pseudonyms used to protect the identities of the children.

**Participant 6 (Zulu, heterosexual female):**

I finished with my boyfriend of 4 years because it was going nowhere. I started a new relationship and just thought I better have an aids test. It is positive and I know I am going to die. I think it is my ex-boyfriends fault and I blame him, we were together for 4 years. Sometimes I feel I can manage, but not always. I don't want to die but I hope he does. My mother and psychologist know, as well as my new boyfriend who decided to stay with me. I still feel bad, I am 24 yrs old and I don't have a future. Everyone seems to have a lot to say about aids but they don't know what it is like if they don't have it. Some days I don't know if I can manage but I suppose I will. I feel dead inside and it is hard to some to work everyday. This thing is going to kill me if I let it, I just don't know if I can stop it. I can't tell people because I know they will treat me badly. There is nothing else now my life will be short.

## Appendix B – an example of a visual display

### Participant 2:

#### Physical

- trigger for testing
- contact with medical professionals = power
- can fight, manageable

#### Virus

- foreign
- incurable, killer
- parasite, alive = symbolic
- separate from mind/spirit
- learn about it = power

#### Secret

- initially a need for it
- keep it inside = destruction = death
- reduces power to fight
- reduces available support
- takes away 'voice'/power

#### Support

- family
- religion

#### Education

- family = support
- helps stay positive
- provides hope, power & courage
- gives him a purpose
- keeps him alive

#### Disclosure

- acceptance and healing
- power: access to media, committees, NGOs, etc.
- liberation, sharing of burden

#### Lack of knowledge

- fear
- death
- lack of acceptance by others and self
- rejection

Survival strategy: to disclose, gain knowledge, and educate as much as possible  
= frustrate the virus = live longer, secret = growth of virus = death.