

**THE SUBJECTIVE EXPERIENCES OF PEOPLE LIVING  
WITH HIV  
AND HOW THESE IMPACT ON THEIR QUALITY OF LIFE**

By

SIMPHIWE TEMPLETON SINKOYI

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## **PREFACE**

This study represents original work by the author and has not been submitted in any form to another University. Where use was made of the work of others it has been duly acknowledged in the text.

The research described in this thesis was carried out in the Republic of South Africa, in Edendale hospital in Pietermaritzburg and in the School of Psychology, University of Natal, under the supervision of Professor Graham Lindegger.

## ABSTRACT

This study explores the subjective experiences of persons who have been informed of a positive HIV antibody test and, from their point of view, explains the meaning and impact that HIV discovery has on their quality of life. In this qualitative narrative study, a racially specific, low-income sample of 10 HIV-infected men and women shared their stories of living with the virus during in-depth interviews. Findings of a multi-staged narrative analysis suggest that for people like those in this study, stigma associated with HIV infection results in the concealment of the diagnosis by the individual for fear of being labeled as deviant from the rest of the community. Secondly, the tragic manner in which these respondents narrated HIV discovery signifies the negative impact the disease has on their quality of life. Lastly, there is evidence for the effectiveness of the primary health-care services on the HIV positive patients. Implications for these findings are elaborated.

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# Chapter 1

## 1.1 Introduction

HIV infection may be considered unique among other life-threatening conditions regarding its influence on the diagnosed individual, in large part due to uncertainty surrounding its social, psychological and medical treatment and its prognosis. Unlike many other life-threatening diagnoses, HIV seropositivity does not present the infected person with an established or predictable prognosis. Rather it introduces the individual to the prospects of increasing ill health in the context of a changed life-style and the very real threat of death after some unknown period.

Furthermore, the notion of living with HIV/AIDS is not only an individual, biophysical condition (Marcus, 1999). It is an illness that sends shock waves into a social web, which has as its nucleus, their immediate families but which extends to more distant relatives, friends, neighbors, colleagues and casual acquaintances. The very source of these shock waves is the mythology with which HIV/AIDS is defined in our society. This mythology tends to reinforce social stereotypes and allocate stigma and blame on the victims by supposedly understanding and caring individuals (Whiteside, 1991). These subjective experiences of HIV seropositivity can have negative impact on the HIV positive individual's self-perception, quality of life, public health and prevention of transmission.

This research is a qualitative investigation of HIV positive people's subjective experiences of living with the antibody virus through an exploration of their narratives of illness in an attempt to assess their quality of life and coping mechanisms. The stories individuals tell about their own or another's illness can powerfully communicate the experiences associated with illness (Garro, 1994). When people tell their stories of illness, they are allowed an opportunity, maybe for the first time, to process the meaning of being HIV positive, narrate steps taken and relate overall experiences of

living with the antibody virus. These experiences may range from their reaction on first discovery of HIV infection, decision to inform or not to inform others and why, to the response of others after disclosure.

This research sets out to examine some of the narratives of being HIV positive, and the various dimensions and characteristics of these narratives. The implications of these findings for the quality of life of people with HIV are explored.

## Chapter 2

### Literature review

#### 2.1 WHAT IS HIV?

##### 2.1.1 HIV and it's history

Aids (Acquired Immune Deficiency Syndrome) was first described in 1981 in USA among homosexual men (Youle, Wade and Farthing, 1988). According to these authors, the review of medical records reveals cases as far back as 1978. Examination of serological specimens hhs proved positive among drug addicts throughout the 70's. According to Beers and Robert (1999), a 16-year old boy in the mid-west USA who died in 1959 has been shown to have been HIV positive. These authors further emphasize that medical records from the Belgian Congo in the 1930's describe the " slim disease" so characteristic of Aids in Africa. This suggests that the disease has been around for a long time, but why the condition has changed from sporadic to epidemic is unknown.

According to Miller (1987), the agent responsible for Aids-Human Immunodeficiency Virus (HIV) is a " retrovirus" (p-I). This means that it belongs to a family of viruses that have a unique ability - they make DNA (Deoxyribonucleic Acid) - the blue print for replication - out of RNA (Ribonucleic Acid). This author further emphasizes that ordinary viruses do not do this, with them the process of viral replication occurs the other way round - DNA produces RNA. Because this family works the opposite way i.e. backwards, they are called retroviruses. It builds off new viruses from the surface of the cell to infect other cells and is responsible for the progressive reduction of the immune system resulting in Aids (Youle et al, 1989). Without doubt, this process affects the normal functioning of the cell.

The retrovirus causing Aids is believed to have been isolated in the late 70's, originally called Lymphadenopathy Associated Virus (LAV) by the French and Human T - lymphotropic virus 111 by the Americans. The current accepted designation is HIV. According to Beers and Robert (1999),

the existence of HIV 1 and HIV 2 has been confirmed. These authors stress that since 1986 it is thought that HIV 2 is more common in West Africa. HIV is a Lentivirus, which means it is slow to replicate and produce pathological effects, which is why an infected individual may continue to live asymptomatic for years until the emergence of Aids.

### **2.1.2 Transmission**

Adams (1989) suggests that the HIV virus is passed on as a result of penetrative sexual intercourse or the injection of blood and blood products or by transmission of infection from mother to baby before or during birth. Although virus particles have been found in saliva, there is no evidence that it has transmitted infection; therefore there is no evidence that kissing can transmit it (Ibid.).

Van Dyk (1992) adds to this explication by emphasizing that HIV is primarily a sexually transmitted virus and is transmitted primarily through penetrating, unprotected (without a condom) vaginal, anal and possibly oral sexual contact. HIV is transmitted only if the virus enters the person's blood stream via the body fluids of an infected individual, which can easily happen owing to the friction that takes place during sexual contact. The delicate membrane linings of body cavities are often torn as a result of friction and the virus is easily able to enter the other person's blood stream through the tear, or mix with blood from the tear.

According to Van Dyk (1992), the HIV virus can be transmitted by other means too, these include exposure to contaminated blood and intravenous drug usage. All donated blood is tested for antibodies. Infected blood is destroyed and the uninfected one can be donated. Although this is a safe procedure, the "window period" (the period after infection but before antibodies are formed) creates problems: infected blood during this period cannot be identified as HIV positive and is therefore not destroyed. There is then, unfortunately, no such thing as "no risk" blood. It is, therefore, the moral and ethical responsibility of people who engage in high risk sexual activities not to donate blood. Furthermore, people who share syringes and needles to inject drugs run a high risk of being injected with HIV. This virus is easily transmitted when needles are shared because drug users infect drugs directly into the bloodstream (Ibid).

### **2.1.3 What does it mean to be HIV positive?**

A positive HIV antibody test means that the individual has been infected with HIV and will be a carrier of the virus for life and thus can infect other people (Beers and Robert 1999). This antibody test does not reveal when and for how long the person has been infected. The test also gives no indication of the stage of infection, nor of the time it may take to develop full-blown Aids.

Van Arkel (1991) suggests that infection has three stages. The first stage is the asymptomatic carrier stage in which a person infected with HIV develops antibodies, is a carrier but displays no symptoms. This is the period in which the virus lies dormant in the body but can still be transmitted to someone else. An HIV positive person can remain healthy for a long time, display no symptoms and be able to do his work. Some people remain HIV positive for as long as 12 years without any manifestation of clinical disease whereas others may deteriorate rapidly and die soon. This is partly attributable to the "differing virulence of the variants of the virus" (p. 16).

The second stage of infection commences when people with HIV antibodies begin to display symptoms. One of the most common symptoms is "general lymphadenopathy" (Van Arkel, 1991, p. 12), or swelling of glands in the neck, arms and groin. Other physical symptoms that appear during this stage are fever, night sweats, diarrhea, weight loss (at least 10 percent of the body mass) etc. These symptoms may be constantly present and are not lethal, only when the person enters the third stage can he or she be said to have Aids. As the virus progresses, the immune system deteriorates increasingly and more persistent, untreatable opportunistic conditions appear e.g. skin cancer. The Aids patient is usually thin as a result of diarrhea, which may last for weeks or even months. Thrush in the mouth may become so painful that the patient is no longer able to eat. The patient is also exhausted and this can result in multiple infections such as shingles, herpes and tuberculosis (Ibid).

## **2.2 Psycho-social effects of HIV infection**

To be informed that one has acquired a life threatening condition can be a devastating blow for the

person concerned (Chidwick and Borril, 1996). For the patient the news may seem almost incomprehensible at first and for many it is only after some time has passed that the full realization may be faced. For others, such realization may never occur either because it is too painful and potentially overwhelming to face, or because there is simply insufficient time left in which to assimilate knowledge. However, for those fortunate to have some time available, the news may be faced and in some cases accepted and assimilated into the individual's world view.

Ohaeri, Campbell, Hesanmi and Omigbodun (1999) write that chronically ill people do not exist in isolation; their care givers, especially the family members, also feel the impact of the disease and treatment. "The psychological and social effects of HIV infection are as varied as the physical symptoms produced by the virus" (Nichols, 1989, p. 235). This means that social support available to the individual is critical in maintaining or restoring their health as well as being a significant factor in reducing the consequences of illness.

According to Nichols (1989), stress response characterized by disbelief, numbness and denial, followed by anger, acute turmoil, disruptive anxiety and depression is typically seen after the diagnosis. The attention of the individual is drawn to matters pertaining to changes in identity and self-esteem, concealment, discovery and disclosure of their HIV positivity. The individual must struggle with issues concerning the meaning and consequences of their HIV status in terms of managing of it's potential discovery and orchestrating it's disclosure to companions, family, friends and relevant others. Moreover, there is also the pressing need to cope explicitly with the felt and potential for enacted stigma associated with their newly emerging and disreputable status as being HIV positive (Alonzo and Reynolds, 1995).

### **2.2.1 Self identity**

HIV infection is a severely stigmatizing illness. It is not that type of a disease that excites public sympathy. Alonzo and Reynolds (1995) emphasize that individuals with HIV and Aids are stigmatized because their illness is associated with deviant behavior, both as a product and as a

producer of deviant behavior. It is viewed as the responsibility of the individual, tainted by a religious belief as to its immorality and thought to be contracted via morally sanctionable behavior and therefore thought to represent character blemish. It is further perceived as contagious and threatening to the community, associated with an undesirable and not aesthetic form of death and not well understood by the lay community and viewed negatively by care providers.

This condition is therefore usually received in lay circles with fear and avoidance because patients usually experience shunning by friends, colleagues, employers and associates. For many, such a public response generates a feeling of being "unclean" or "dirty" (Miller, Weber and Green, 1986, p. 136). These patients may, as a result, avoid discussing their diagnosis with others for fear of the anticipated response occurring. This is because their current life is characterized by the experience of worthlessness and possibly guilt resulting in feelings of being a constant failure, incompetent and inadequate to deal with the demands that life may impose on them. Similarly, such persons may avoid making future plans or social contact because they may believe that they are unworthy or unable to make the best of such opportunities. Miller et al (1986) adds that self-esteem is further affected when HIV positive patients experience symptoms. They may withdraw from social or work situations because they feel too self-conscious or unattractive.

Crossley (1999) maintains that the kinds of questions troubling people today center around concerns with the meaning of life, the meaning of self, where we are going and what we are doing. These "existential predicaments" (p. 1686) of modern life, our fears of a terrifying emptiness, of loss and meaninglessness dominate our age, and yet they are different from the kind of experiences in previous civilizations. In earlier times, these kinds of questions were not on the agenda because people lived within "unchallengeable" frameworks of meaning, which made "imperious" demands on them (Ibid).

For example, nowadays HIV testing represents, among other things, a social responsibility. Danziger (1999) conducted a study comparing the social impact of HIV testing in Britain and Sweden. He discovered that in Sweden the HIV test marks the beginning of a series of interventions designed to



ensure that people with HIV do not pass it on to those who are not infected. Individuals who think they may have been at risk for HIV infection are required by law to go for a test whatever the person's preferences might be. In Britain the emphasis is on individual rights, with the right to fight out one's HIV status, but also, through the emphasis on voluntarism, the right not to know one's status. In contrast to Britain, Sweden's HIV precaution program places a great deal of emphasis on identifying HIV infection, because prevention is seen mainly as the responsibility of infected people (Ibid).

Lastly, Alonzo and Reynolds (1995) suggest that while other illnesses or character blemishes can be said to differentially stigmatize, HIV infection and Aids are rather universal in their preponderant negative evaluation. According to these authors, although the stigma associated with HIV/Aids is overpowering, individuals with this illness do not necessarily experience the same degree of stigma. Differentials in stigma experience can be explained to a large extent by variations in individual social identities and attitudes confronted in one's social networks and reference groups. For example, an individual with strong ties to the gay community may perceive less HIV related stigma than an individual with stronger ties to non-gay communities.

### **2.2.2 Relationships**

In 1987 Pollak, as quoted by Kelly and St. Lawrence (1988), conducted a study that discovered that HIV seropositivity led to dissolution of existing relationships among both heterosexual and homosexual couples. According to this researcher, many HIV positive persons spend more time in solitary activities after they have learned they are seropositive and most may fear that their HIV exposure would negatively affect established relationships. They may therefore hesitate to inform their partners, fearing they would precipitate a break-up in the relationship.

Kelly and St. Lawrence (1988) argue that isolation is not necessarily the inevitable outcome of positive HIV test results. According to them, in well-developed and more affirmative environments test disclosure can be more constructive and serve as a means for generating social support. In other

less-informed backgrounds avoiding reactions of others can unwittingly heighten distress and leave the HIV positive person feeling shunned, vulnerable, and isolated from the very persons who had previously been a dependant support group.

Gorna (1996) maintains that women who are HIV infected tend to have acquired the virus in relationships where they were monogamous. During the time of highest infectivity a woman is more likely than a man to have sex only with one man who infected her, and not pass on the virus. By the time the woman reaches the symptomatic phase, according to Gorna (1996), the sexual partner will have died since he was infected first.

Minkoff, DeHovitz and Duerr (1995) add that a woman bereaved by the loss of a loved one to AIDS, loses both her relationship and the person on whom she relied on for care when she was ill. If she had cared for the partner during the terminal phase of illness, she may have fears about her own death or about abandonment. This issue is complicated even more if there are children to consider. Because of the distribution of HIV infection, such children tend to be young. Women are bereaved by losing a shared future with children and by the additional burden of knowingly leaving orphaned children

### **2.2.3 Family**

According to Jager (1988) how a family reacts to learning of its member's HIV infection depends very considerably on the quality of the relationship. Most traditional African monogamous or polygamous families are comprised of parents and children (the nuclear family), frequently living in proximity to grandparents, siblings and other relatives (the extended family or kinship groups). Such families have formal standing and responsibility for care taking in law and tradition. Fleming, Carballo, FitzSimons, Bailey and Mann (1988) stress that HIV status creates a family disruption, which is pervasive and enduring. It is felt at all levels of individual and collective life within the family. Whether the family accepts or rejects the person is irrelevant, disruption will be experienced (Ibid).

The first disruption for all families comes with recognition of the social and personal implications of HIV status or diagnosis. Knowledge of HIV status invariably leads to revelation of behaviors or practices which heretofore were unknown, or were denied, and not discussed by family members. For example, it usually happens that the family is not aware of the member's dating status or has never been discussed and hence this news is received with great shock. Once HIV status is known to the person he or she must undergo the stress of deciding when or if to tell the family. When family members know, depending on the quality of the relationship, they face the stress of deciding whether to accept or reject care-taking responsibilities (Jager 1988).

When the accepting family agrees to care for the infected member, emotional and material resources of the family are immediately affected. Routines are disrupted, particularly as disease progresses. Stress is experienced by the entire family or household, and is not limited to the primary care taker. Family disruption also occurs because of the infected person's reaction to his or her diagnosis. Depression, mood swings, anxiety and projected hostility onto caretakers are rarely understood by the family members. Arguments, refusal to take medications, threats and tension between family and patient can build to a point of rejection even though there was acceptance previously. Some families do not agree to offer care at the time they learn of the diagnosis. In these families disruption in another form is apt to occur (Jager 1988).

Not all family members will agree with the decision to reject, and there will be internal dissent. According to Jager (1988), rejecting families are likely to maintain traditional sex role behaviors and standards of morality, rigid division of power and authority between parents, and views of proper family life supported by traditional and fundamentalist religious beliefs. Families who reject are also apt to be highly sensitive to the opinions of the extended family, kinship groups, or neighbors. Concerns about being viewed in a good light by outsiders is a major factor in a decision to reject (Jager 1988).

The rejection by family members usually has negative effects for the HIV positive person. This is because they become deprived of the immediate social support when they need it the most. Rene,

Skinner, Lee and Kazis (1999) point out that individuals who lack social support tend to have lower levels of psychological well-being and higher incidence of physical illness.

According to Castro, Orozco, Aggleton, Eroza and Hernandez (1998, p. 1481), "neither solidarity (accepting) nor discriminatory (rejecting) responses are pure responses. Instead they are often intermixed or intertwined, the precise balance between them being influenced by the characteristics of the actors involved and the social structures that generate them." From the study they conducted in Mexico to analyze the family responses to HIV/AIDS, they discovered that supportive responses were closely associated with kinship and gender. Men who provided support did so mainly through the resources they obtained from their jobs (i.e. money, access to health services etc). Women on the other hand, provided support by taking care of the sick at home. Fear was an important element in shaping family reactions and it's effects often appeared in the form of discrimination. Here fear was most often associated with an unwillingness to be close to the patient and with the taking of extreme safety measures in dealing with the HIV/AIDS patient. In this kind of atmosphere family conflicts deepen, giving rise to even more negative responses.

#### **2.2.4 Work**

According to Hartwig (1995), it has been taken as normal that a person applying for employment or effecting individual life insurance, should provide evidence of good health through a questionnaire, a medical examination or perhaps more extensive tests such as x-rays or blood tests. Requiring an HIV test is merely an application of this principle. These authors argue that it has long been accepted that people with severe health problems (e.g. very high cholesterol or very high blood pressure) are not fit for work. HIV is not different to these in its impact on life expectancy (Ibid).

Hartwig (1995) quotes a study conducted by a university clinical and research unit in New York. This study confirmed that asymptomatic seropositive people show increased risk of disability. It found that poor neuropsychological performance during the phase of asymptomatic HIV infection may indicate increased risk of early functional morbidity. These authors maintain that the statistics

from Malawi illustrate the extent to which employers can expect a progressive increase in the cost of employee benefit arrangements that provide any sort of insurance benefit, group life schemes, pension funds and medical aid funds.

Most employers are not willing to bear the increased costs themselves hence they resort to conducting adequate HIV testing before taking on such risk. This leaves the HIV positive individuals feeling excluded and treated differently. This practice is, however, illegal in South Africa and it is in contravention of the Employment Equity act of 1999. Campbell and Williams (1999) cite an example of similar situation in which the Chamber of Mines and the Unions disagreed strongly with the government's position regarding the exclusion of the Malawian HIV positive employees. They insisted that HIV positive workers already in employment should not be repatriated although the Chamber of Mines still maintained that the HIV positive people should not be recruited to new jobs.

### **2.3 Psychological and psychiatric effects**

According to Bartlett (1995) 20-30 percent of patients with HIV develop a major depression at some time during the disease, and this bears little relationship to any prior history of depression or to a family history of depression. Depression is most common at advanced stages of HIV infection. Suggestive symptoms are a sudden change in mood, energy and self-attitude with morning insomnia, anorexia, decreased libido, low energy, flat affect, feelings of guilt and self-denigrating attitude. Delirium is also common and is distinguished from dementia by acute onset, "waxing and waning" mental state, and disrupted sleep, speech that is often incoherent, and reduced awareness. Most patients with delirium respond well to low-dose neuroleptics agents.

The psychological impact of living with HIV is immense, involving not only the potential burdens of physical deterioration but also the stress of accompanying life style and role changes. Psychological processes involved in adjusting and adapting to HIV infection are important not only because of their centrality to the coping individual but because they directly affect the success of treatment and prevention. It is well known that psychological health influences physical health and

that psychological factors are relevant to a wide range of behaviors that directly bear on treatment, such as patient compliance with medical regimens (Minkoff et al., 1995).

Hearing that one is HIV infected is a traumatic experience. Minkoff et al (1995) suggest that emotional reactions of the patient to this diagnosis vary depending on their risk category. Those who contracted HIV by means of high-risk behaviors that they knowingly engaged in (e.g. multiple sexual partners, intravenous drug use) face different issues than those who contacted the disease through other mechanisms (e.g. blood transfusion or monogamous sex with an infected partner who was thought to be uninfected). For the former group, a positive HIV diagnosis incurs a stigma associated both with the disease and with the fact that the person engaged in high-risk behavior. These people need to deal not only with the fact that they have a life-changing illness but that they may have incurred the disease through their own actions. This knowledge can result in feelings of guilt, self-directed anger and blame. By contrast a low-risk individual infected with HIV may experience more outward-directed anger. In this group there is usually redirection of blame, anger and shifts in responsibility for the disease in that the patients may hold their partners responsible for their suffering (Ibid).

## **2.4 Coping with HIV and Quality of life of HIV positive patients**

### **2.4.1 What coping means in this context?**

Allison, Locker and Fein (1997) define coping as constantly changing cognitive and behavioral efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person. Based on Folkman and Lazarus they categorize two fundamental forms of coping each according to its function: problem-focused coping processes directed at managing or altering the problem causing the distress, and emotion-focused coping processes directed at regulating the emotional response to the problem.

In this context, the latter form of coping is emphasized mainly because the stressor (HIV

seropositivity) is appraised as beyond control. In this, as in any given situation, the coping strategies used by an individual are determined by several factors such as the person's available resources. This involves many factors such as beliefs, social support, commitments, problem solving skills and material resources. Some of those coping strategies that will be discussed in detail include the following:

#### **2.4.2 Concealing the diagnosis**

According to Alonzo and Reynolds (1995), HIV positive individuals tend to conceal their diagnosis as a defense against enacted stigma associated with the virus itself. Those individuals in the asymptomatic phase harbor feelings of shame, self-blame and fear of rejection or abandonment by friends, neighbors, co-workers and employers. By concealing one's HIV status, these authors add, the individual attempts to protect his or her self esteem by avoiding episodes of enacted stigma, though there may be other negative consequences of doing so. Firstly, it is emotionally exhausting. "The stress of living a double life is a heavily felt burden especially if interacting in both straight and gay settings" (Alonzo and Reynolds, 1995, p. 309).

Secondly, by keeping the diagnosis secret, the individual is deprived of social support from his or her social network that presumably would normally be available to him/her. Thirdly, by failing to disclose the individual also risks engendering the hostility of others when they finally learn that the individual is HIV positive and they were not informed previously. Fourthly, the individual may be motivated to refrain from activities that signal diagnosis, such as delay in seeking appropriate health care or participation in HIV support groups. Lastly, the individual may be highly motivated to sustain participation in social and occupational activities so as not to let others know or be suspicious of his or her HIV status. The individual may engage in activities that dismiss and deny the diagnosis, such as unprotected sex with unknown partners or sharing needles. In so doing, the individual essentially conceals his HIV positivity but this will necessarily come at the cost of placing others at risk (Alonzo and Reynolds, 1995).

### **2.4.3 The impact of social support**

According to Minkoff et al. (1995), social support is related positively to overall well being and negatively to distress and depression in chronically ill patients. These authors distinguish between four types of social support. The first is tangible support, which refers to assistance in the provision of material goods and services (such as assistance with money, transportation, babysitting). The second is emotional support, which refers to support in the future of providing empathy, understanding and caring. The third is informational support, whereby an individual can readily consult with others about information that she needs about HIV/Aids, treatment regimens, and other issues important to her. The fourth is companionship support, in which an individual can rely on others for companionship (e.g. going to movies and other social activities). Each of these forms of support can be crucial and there are large individual differences in the extent to which such support networks are in place and accessible to the HIV positive. Individuals with relatively impoverished support networks are at much greater risk of poor adjustment and inadequate coping styles.

"Social network is a measure which identifies three main sectors of social support and involvement : family, friends and community" (Gliksman, Lazarus, Wilson and Leeder, 1995, p. 811). According to Hall and Nelson (1996), social network refers to the structural aspects of a person's support system such as the number and type of network members and social support refers to the functional aspects of a network, including the various types of support that are received and given. Hall and Nelson (1996) identify two main discussions of positive social support and these are emotional support and problem-solving support. According to them emotional support refers to expressions of warmth and approval while problem-solving support means advice and or directive guidance which can help a person cope with and solve problems in living.

Alonzo and Reynolds (1995) maintain that individuals find solace in social support groups, which can provide a context that enables the stigmatized person to feel normal. According to these authors, the accepting nature of self help and support groups with their sense of a "shared stress" (p. 311), may serve as a respite from felt stress and stigma. Because support groups are comprised of others who share the same symptoms or disability, they can provide "tricks of the trade" and sanction. They



may constitute a community of their own in which members share a stigma and demonstrate that they are accepting and accepted people. At the same time this provides a forum for the individual to be a, "hero of adjustment in the face of adversity visited upon them over the course of the stigma trajectory" (p. 311).

Mathews, Stansfield and Power (1999) stress that since the mid 1970's there has been increasing interest in the relationship between social support and health. Social support, as measured by social network variables, has been shown to predict all causes of mortality among adults of all ages. As well as mortality, social support has been related to a wide range of health outcomes including well being and depression, improved immune status following drug therapy for cancer, anorexia and bulimia nervosa and various chronic conditions such as rheumatoid arthritis and diabetes. The same applies to HIV related conditions, patients verbalize their need for social support as central to their adaptation process (Ibid).

Rene et al. (1999) acknowledge this notion by emphasizing that individuals who lack social support tend to have lower levels of psychological well-being and higher incidence of physical illness. According to these authors, lack of social support constitutes a major risk factor for mortality. Social support also affects health by mediating in the adverse effects of social stressors. Social stressors are defined by these authors as any environmental, social or internal demand which requires readjustment of an individual's behavior patterns, are strong predictors of physical morbidity, mortality, symptoms of psychological distress and psychiatric disorder. However, Rene et al (1999) stress the damaging mental and physical health effects of social support can be largely mediated by the presence of an individual's social support.

## **2.5 Quality of life**

According to Koch (2000), quality of life assumptions were introduced in the 20<sup>th</sup> century by advocates of the eugenics movement in the United States. The general argument was that some persons were so disabled such that their deaths were socially preferable to the continuance. Eugenics

could mean judging both who was "better not born", and deciding who was "better-off-dead". Chen and Hunter (1996) related quality of life to the satisfaction of individual need for growth, well being, self esteem, freedom and the pleasures of meaningful relationships and meaningful work. The above mentioned factors have encouraged the application of the quality of life concept in health related investigations.

According to Chen and Hunter (1996), public health campaigns, rising standards of living, and the development of immunizations and anti-biotics have led to a shift in medical attention in parts of the developed world from the cure of acute diseases to the management of more complex, long-term conditions (e.g. hypertension, cancer, HIV). These diseases are often resistant to simple cures, so physicians must settle for treatments which mitigate symptoms and/or prolong life (Ibid).

Allison et al.(1997) considered the quality of life the people in such chronic conditions will be leading. They suggest that these individuals will have a worse feeling of well-being than other individuals whose life experiences have been mainly positive. As a result this will impact negatively on the person's self concept in that he will respond by downgrading himself such that he is unable to feel good. Subsequently his ability to cope with challenges, problem solving and cognitive skills and self control will deteriorate. These factors have been highlighted because they are the phenomena best understood in relation to QOL in this context.

Bush, Hagerman, Donaldson and Sullivan (1995) define quality of life (QOL) as a multidimensional construct composed minimally of four domains:

- ⇒ Physical function (daily activities, self-care, mobility, role activities).
- ⇒ Psychological function/emotional/mental state (distress, mood perceptions of well-being satisfaction, happiness).
- ⇒ Social role function/ability to engage in normative social interactions and occupations (interpersonal relations, sexual functioning, family dynamics); and
- ⇒ Disease/treatment symptoms/somatic discomfort (pain, nausea, etc.)

## 2.6 The role of counselling

HIV positive persons are often forced to make many difficult psychological and social adjustments. They are faced with painful illness and treatment, possible loss of a job and income, loss of independence, and a reassessment of social and personal needs. Relationships change - some become strained, others develop deep supportive, meaningful ties. It is essential that patients, family, and friends avail themselves of the psychological and social support of the community. According to Aggleton, Davies and Hart (1990), counseling of individuals has some role to play and a key part in work with HIV zero-positive people and Aids patients. According to them, the work has two key elements :

- ⇒ helping individuals change their behavior in such a way as to reduce spread of the virus,  
and
- ⇒ reducing the stress on individuals and their loved ones while improving their quality of life.

Gottlieb, Jeffries, Mildian, Pinching and Quinn (1987) emphasize the significance of pre-test counseling as mainly aiming at offering basic education about the virus, including discussing the risk of developing Aids if the test is positive. These authors further state that it covers the ways in which the virus can be transmitted. Specific transmission reduction advice is offered and the individual is advised on ways of staying well and in good general health. Advice is offered on identity and reduces anxiety and depression. There is a good deal of advice on general issues such as contact with medical practitioners and dentists.

In a real sense, everyone involved with a patient is likely to be involved in counseling him/her. However, it is very useful to have one or more people who will take responsibility for carrying out the bulk of counseling work. In hospitals, counseling work is offered by people who possess specialized skills including:

- ⇒ knowledge of HIV and ability to keep up with the rapidly developing field.
- ⇒ basic counseling skills.

- ⇒ the ability to work with a wide range of other professionals and to communicate clearly with them and,
- ⇒ the ability to recognize patients who need more specialized referral for instance, those who have become very depressed (Gottlieb., et al, 1987).

While not de-emphasizing the significance of pre-test counseling Miller et al. (1986) suggest most counseling is likely to be done when test results are known. The most sensible way to handle this is for the doctor to give a definite appointment for the patient to get his/her results. This can be arranged so that the counselor is available to see the patient immediately after he or she is told the results. These authors further emphasize that it is worth counseling sero-negative people as well as sero-positives. Sero-negative people seeking to establish their status are clearly concerned about the risk and are usually very receptive to sensible advice. It is important for the counselor to have all available information on a patient. If a patient is being seen over time it is vital that the counselor has information on his or her current health and any changes in this (Ibid).

## **2.7 Narratives of HIV infection**

Life-threatening illness such as HIV/Aids, usually threatens people's sense of identity, their relationships with family and with others, their work and cause "temporal framing of their lives" (Ezzy, 2000, p. 605). In response to this, people often experience transformations in their lives in terms of values, spirituality and life priorities. Narrative theory has been increasingly utilized to study the subjective experience of illness. According to Ezzy (2000), narratives are the primary license by means of which human existence is rendered meaningful.

Human life is seen as something that can be depicted in stories. The stories that are told about life are measured by the adequacy with which they describe what happened in life as it is lived. Therefore, one can make an assumption that life and story are internally related. This means that the meaning of life can not be determined outside the stories told about it. Thus, life informs and is informed by stories. Josselson and Lieblich (1993) suggest that the relation between life and story

is "hermeneutic" in that the implicit meaning of life is made explicit in stories. From the hermeneutic point of view human life is interpreted in stories, "it is the process of narrative interpretation"(p. 2).

A recognized collection of research acknowledges the importance of the story or narrative as a way of dealing with traumatic events particularly experiences of illness. According to Garro (1994) the stories individuals tell about their own and another's illness can powerfully communicate the experiences associated with illness. In their narratives, persons may attempt to make sure of what has happened, describe actions taken and why, and relate how the illness has affected them. This happens partly because narratives are embedded in the context of individual lives (Crossley, 1999). The experience of illness may also change the way individuals think about themselves, their present and future as well as their past. In personal narratives of illness, often what is told cannot be seen simply as a story of an illness but the story of life altered by illness (Ibid).

In Crossley's (1999) terms when ill people tell their stories, they are engaged in a process of empowerment. According to this author, over the past twenty years or so, rapid changes in economy, society and culture manifest in the health arena have served to challenge biochemical dominance and led to the definition of patients as "experienced subjects who can contribute knowledge and take active part in decisions" (p.1657). Marshall and O'Keefe (1995) further stress that in the past when people became ill, their only responsibility was to try and get well again. In contemporary culture, however, the ill person is encouraged to be more reflexive and to take responsibility for what illness means in his or her life. Hence the telling of a story constitutes a moral imperative and involves a profound assumption of responsibility (Ibid).

Narrative theory studies the subjective experience of illness. This reflects a more general move to the narrative understanding of human action in psychology. Narratives are the, "primary scheme by means of which human existence is rendered meaningful" (Ezzy, 2000, p. 605). This theory provides an innovative and useful way of approaching the subjective aspects of human experience in general and the illness experienced in particular. We may as well tell stories of our lives and this is of fundamental importance in the clinical world.

### 2.7.1 Different types of narratives

Different authors suggest different types of narratives but some overlap with regard to similarities thereof (Marshall and O'Keefe, 1995). Drawing from the study of people living with HIV in Australia, Ezzy (2000) distinguishes three different narratives that people use to make sense of their illness experience. These include:

- ⇒ Linear restitution narratives which Crossely (1999) calls normalizing narratives. Both these authors agree that people using this type of narrative attempt to narrate and live a normal life in spite of an HIV diagnosis. They may narrate activities that represent a continuation of planned goals that they had held prior to HIV diagnosis e.g. completion of a course of study, buying a home, etc (Ezzy 2000). Some people refuse to believe that their lives have been shortened whilst others may accept the reduction in time available to achieve their goals, but stress that these normal goals were carefully framed to be worthwhile within the shortened time frame (Ibid).
- ⇒ Linear chaos, tragic or stories of loss. These stories are characterized by expressions of anger, depression, isolation and social disolation (Ezzy, 2000). They carry within them elements that are common to other types of trauma i.e. perceived threat to one's life and perceived responsibility for the death of others, the empty present and the bleak future, attempted suicide and present suicidal ideation (Steven and Doerr, 1997). Thinking and planning about the future may be avoided. When asked about the future, respondents may express that there is no future for them (Ezzy, 2000).
- ⇒ Polyphonic or conversion or growth stories. These stories are about transformation and transcendence (Marshall and O'Keefe, 1995). They are characterized by overlaid, interwoven and often contradictory stories and values. The narrators embrace many contradictions and tensions in their accounts rather than suppressing them. Stories of loss and rejection may be mixed with celebrations of the insight and self- understanding HIV had provided (Ezzy, 2000). The future is an imagined world of potential change and temporal horizon extends into infinity (Marshall and O'Keefe, 1995).

In conclusion, Crossely (1999) argues that whatever type of a story HIV positive individuals choose to use help them adapt to their diagnosis by limiting the sense of vulnerability imposed upon them by the threat of a potentially terminal illness.

## Chapter 3

### 3.1 Rationale

The purpose of this study was to examine the quality of life of the people who have received an HIV positive diagnosis through an investigation of their narratives of illness. Finding out one is HIV infected is a significant discovery. In receiving an HIV positive diagnosis individuals are exposed to news of "prodigious personal experience" (Stevens and Doerr, 1997, p. 523). Patients' perceptions of such pivotal health information may affect the actions they are able to take. Initial subjective experiences of HIV positivity can have ramifications for future outcomes of longevity, quality of life, and prevention of transmission (Ganz, Schag, Kahn, and Petersen, 1994).

Interventions and resources designed to serve people at diagnosis and early in the course of HIV illness must be based on understanding HIV discovery from an insider's view (Stevens and Doerr, 1997). This study was undertaken to explore HIV infection from such a vantage point. The questions guiding this research were:

- a) What are the HIV positive people's subjective experiences of being informed of their HIV positive status?
- b) How did these people perceive the news that they have HIV?
- c) How do the HIV positive people describe the impact this news has on their lives?
- d) What is the quality of life of people who are HIV positive and what accounts for this Q.O.L?

These questions were examined through an exploration of the illness narratives of being HIV positive. The following formed sub-aims of this research:

- a) To assess the impact of social support on the psychological adjustment of these patients.
- b) To determine the patient's fears and insecurities with regard to the present scenario.
- c) To investigate the extent of the impact on the patients' sense of self, identity, coping strategies and future aspirations.



- d) To measure the effect of the services received by these patients at the CDC on their experience of themselves physiologically and emotionally.

### **3.2 Tentative hypothesis**

While this research does not aim to primarily test hypotheses, there were some preliminary hypotheses. These included the following:

- a) The HIV positive individuals fear to disclose their present status to other people in both family and community settings to avoid being stigmatized and isolated.
- b) A diagnosis of HIV causes the patients to lose hope in life, to consider themselves useless and further shuts their hope for the future.
- c) The services rendered at the Communicable Disease Clinic (CDC) will prove to be beneficial to the HIV positive patients.

## **Chapter 4**

### **Methodology**

#### **4.1 Introduction**

The term methodology refers to the way in which we approach problems and seek answers (Taylor and Bogdan, 1984). In social sciences, the term applies to how one conducts research. Our assumptions, interests and purposes shape which methodology we choose. The main purpose of this study is to describe the HIV positive people's experiences of living with the antibody virus and, "from their point of view, to explain the meaning and impact of discovering that one is HIV infected" (Stevens and Doerr, 1997, p. 523).

The need for an investigation into the quality of life of HIV infection is partly to improve the quality of life of HIV positive individuals. This means that the researcher attempts to bring to light the experiences of the HIV positive individuals as a basis for improving their quality of life.

The present investigation was conducted in Pietermaritzburg at Edendale hospital's Communicable Disease Clinic. To the best of the author's knowledge, no other research of this nature has been conducted on the chosen site prior to this study. Nevertheless, further investigations into the area can provide comparable data.

#### **4.2 Narrative Method**

Narrative theory studies the subjective experiences of illness (Ezzy, 2000). Because the narrative approach encourages self-expression and acts as a mechanism to effect transformation of self (Crossley, 1999), it was deemed appropriate to utilize in this study.

Narratology is the theory and systematic study of narratives (Currie, 1998). A narrative is the oral or written discourse that undertakes to tell of an event or a series of events, experiences and feelings (Genette, 1980). It is an act of communication in which the imparting of the transitive view of self

and the world is the effect of the message produced (Coste, 1989).

Narrative theory provides an innovative and useful way of approaching the subjective aspects of human experience and illness experience in particular (Ezzy, 2000). The stories that people tell enable them to act with a view to shaping their own future. When using the narrative method, the interviewer takes the role of directing the discussion to some extent so that the required information can be obtained, but the respondents are allowed to talk and cover the area in their own terms and from their own position. According to Katzenellenbogen, Joubert and Yach (1991), the major advantage of using this method is the space for personal explanation and detail that it allows the respondent. In addition, the individual focus allows the interviewer to draw out more detail while the respondent is talking and thinking about the subject.

Considerable preparation needs to go into the interview prior to going into the field. Besides developing an adequate interview schedule, the researcher needs to be clear on the purpose of the research, have a good knowledge of the community to be researched and have read considerably on the area to be researched (Denzin and Lincoln, 1994). Interviewers may have to prepare themselves emotionally as they often have to deal with difficult and emotive issues from the respondents. Most commonly, the interviewer will enter the field with a list of points to be covered in the interview. These points give direction but ideally should not inhibit the interviewer from going into other areas if they appear to be important during the course of the interview. No sequence is imposed and each point can be the beginning of a series of probing questions. The greater the level of structure provided the more the spontaneity of the interviewee is inhibited (Katzenellenbogen, et al., 1991).

Lothe (1991) stresses that when organizing the encounter, the respondent should be reassured as to the credibility of the interviewer and the nature of the research should be explained. A person's unwillingness to be interviewed should be respected, but the problems should be enquired about and answered if possible. According to Phelan and Rabinowitz (1994), the initial phase of the interview is very important and this is the time where initial trust is established or lost. Openness and frankness over the nature of the research will assist trust at this point. Confirm that the person is agreeable to

being taped, reaffirm the nature of the research and reestablish your credibility. Privacy and quiet should be ensured where possible. The atmosphere should be kept cordial and open. The time has to be noted so that all the required material is covered in the time allocated. An interview should preferably not last more than an hour, can rather be carried on at a later point if more time is required (Ibid).

Termination of the interview needs to be handled with great discretion and care. Any emotions and hopes that the interview may have raised need to be respected and talked through, as appropriate. At the end of the interview the respondent needs to be informed of where the research is going from this point, should be reassured about confidentiality and, where possible, the offer of later feedback should be made. Finally, this is the ideal time to present the respondent with consent forms, if any, to be signed (Katzenellenbogen et al., 1991).

### **4.3 The Sample**

This research took place in Pietermaritzburg, Kwazulu Natal. The Communicable Disease Clinic in Edendale hospital in Pietermaritzburg is a service center for patients with HIV and HIV related sicknesses. This clinic was picked purposefully to represent the entire population and as a convenient site for the research of this nature. Permission to conduct this research was obtained from the hospital authorities. A total of seven female and three male patients participated in interviews during data collection. Information redundancy (Stevens and Doerr, 1997) was used as guiding principle to determine sample size.

This sample comprised mainly of black, Zulu speaking patients from both rural and urban backgrounds. The mean length of time since being informed of their HIV positive status was 3 years, with a range of 6 months to 6 years. 80% of the patients interviewed were unemployed with only 20 percent in full time jobs. The mean age was 28, ranging from 23 to 46. 80% of the sample had not completed high school.

The sample was regarded as a convenience sample, because it relied on willingness to consent to be interviewed. The limitation of this type of sampling is that it may be impossible to evaluate the extent to which samples are truly representative of the relevant population, and secondly, it may be difficult to compare studies.

#### **4.4 Procedures**

Patients were approached during their regular medical visits to the clinic. A registered nurse would introduce the researcher to the patients in the waiting room. The researcher would then explain to the patients that he is conducting a study to evaluate the quality of life and the needs of an HIV infected population. He explained that the patients were under no obligation to participate but that consent to do so would be highly appreciated. Issues of confidentiality and anonymity were explained to the patients. Each respondent was required to sign informed consent forms. Volunteers were each interviewed in a separate room provided for the researcher by the clinic staff. All interviews were tape-recorded. Consent to use the tape recorder was obtained from each patient.

#### **4.5 Data Collection**

Under conditions of informed consent (Stevens and Doerr, 1997), each of the 10 participants was engaged in an in-depth, open-ended interview of 1-hour duration during which he/she was encouraged to share his/her story of living with HIV. Within this broader inquiry, each participant was asked to relate a story of his/her life concerning their diagnosis, starting with when and how they found out and what that experience had been for them. After the story, and depending on how much the patient covered, the interviewer would prompt to inquire further with questions such as:

- Can you please relate to me what were the first things that went through your mind when you received the news, please try and tell me everything.
- Is there anyone you told about this? If not, can you tell me why and how they'd react if you told them?
- Please tell me about your family.

- Please tell me how you feel about your body since this diagnosis. Are there any changes that you want to talk about?
- What impact did this situation have on your future plans?
- Now that you find yourself in this situation, do you hold anyone responsible for it?

#### **4.6 Data Analysis**

Interview audiotapes were transcribed verbatim. Data were then analyzed using multi-staged narrative analysis technique (Stevens and Doerr, 1997). With each stage, purposeful successive readings of the interview transcripts were done to analyze story type, themes, content and aftermath. In this way, there was layering of systematic analysis, which added to the rigor of the study. First, the type of each story was demarcated to whether it was a normalizing, creative, tragic, transformative etc. Second, the main themes that emerged in each narrative were analyzed in depth, scrutinizing the person's experience, understanding of and feelings about HIV discovery. Third, each participant's sense of self and identity, their body, relationships with family and others and work experiences were analyzed. Fourth, the main role players in the narrative and what role they played were identified and elaborated.

Fifth, the critical turning points as well as how these are shown in each narrative were compared and contrasted. Sixth, the relationship between each of the role players and the turning points in the narratives were explored. Lastly, for each of the respondents' narrative, it was determined whether there were different voices of self and where those emerged.

## Chapter 5

### Results

#### 5.1 Story type

Initially stories were analysed to assess the types of narratives employed, both dominant and subordinate. These stories comprised of the tragic, somewhat tragic, normalising and creative types. See Table1.

**TABLE 1.** Rank order of story-type by subjects.

Story type	SUBJECT									
	01	02	03	04	05	06	07	08	09	10
Tragic	1			1			1		1	
Somewhat tragic	2		1			2	2	2		1
Normalising		2			1			1		
Creative		1			2	1				

**TABLE 2.** Frequency of dominant story-types in narratives.

STORY TYPE	FREQUENCY
Tragic	4
Somewhat tragic	2
Normalizing	2
Creative	2

### 5.1.1 Tragic stories

About 40 percent of the stories given by the respondents were purely tragic narratives which means that HIV discovery was viewed by these respondents as a traumatic event. Emotional shock, disbelief, heartbreak, anger and feelings of helplessness accompanied their immediate hearing of the words: "I am sorry to tell you, but your test results came back positive. You have HIV." They experienced a sudden shift in their meaning of life, their perception of themselves and had a problem with their present state of affairs.

It is assumed that these stories emerged as tragic because of their preconceived knowledge about the dangers associated with HIV infection especially on life expectancy. Ignorance about the latest developments concerning care and treatment of HIV positive individuals may also have contributed to their negative feelings about themselves. They also perceived themselves as capable of bringing death to others and thereby experiencing themselves as outcasts in the community.

This story type was only common among women from ages 26 to 29 who had not finished their high school education and who were unemployed. There seemed to be a link between these women's subjective experiences and their socio-economic backgrounds. Even though the following aspects of HIV discovery were found in other story types, they were more emphasized in these stories of loss i.e. tragic.

#### 5.1.1.1 *Shift in the meaning of life.*

The traumatic element of threat to one's life was prominent in the stories of HIV discovery. These patients appeared to be so overwhelmed by the news of HIV infection that a dramatic change in their meaning of life occurred. A 23-year old single woman said:

"This came as a complete shock to me, I had a problem accepting it, I was heartbroken because it seemed like there was no one I could turn to, and everyone avoided me. I had to deal with this issue by myself in the hospital and resolve it within me. It disturbed me a great deal but I felt right now, my life belongs to my mother, whatever I do with my



remaining life is for her."

For some, death was considered a better alternative. The following is an example from a 46-year old woman's narrative:

"I became so angry that I wished to die. I even considered committing suicide. I was devastated but I thought about my children, I did not want to leave them with no one to care for them."

#### *5.1.1.2 Capable of bringing death to others.*

Some of these patients viewed themselves as agents of mortality and as such outcasts in the community. This seemed to have a detrimental effect on their self-image and their self-identity. A 27-year old single man said :

"I feel sorry for the other girls I slept with without safety precautions who did not know that I'm in this situation."

Another 46-year old woman felt infectious towards her children:

"Now I have to take safety precautions while doing household chores, like if I get a cut I must not touch food or other eating utensils to avoid infecting my children."

Though these experiences were evident in the stories told by the majority of the respondents, other narratives were not completely tragic and were characterized by more than one story type each. These narratives described here were then regarded as somewhat tragic stories.

#### **5.1.2 Somewhat tragic stories**

About 20 percent of the stories in the sample were not completely tragic but somewhat tragic. This

means that their tragic nature would be intermixed with the Normalizing and the creative or polyphonic expressions that will be described later on in this chapter. These were much more stories with some elements of hope though the trauma was felt one way or the other. A single woman, 27, said:

"I did not think about committing suicide because the nurse here told me that there are tablets I can get and if I comply with them I may last a while."

Some were overwhelmed by disbelief and could not acknowledge the bad news. They stayed for some time with the hope that this may be some mistaken diagnosis. A 26-year old man said:

"I was totally devastated, I couldn't believe this was happening to me such that I stayed the whole month hoping that there may have been some mistake in this diagnosis. I went to three different clinics to take HIV tests and it was only when they all came back positive that I finally accepted the news."

For others the CDC provided a sense of togetherness, acceptance and comfort. The following is an example from a 26-year old woman's narrative:

"When I came to this clinic, I found out that there is a lot of other people suffering from the same condition as me and so I'm not alone in this. It came as a big shock, I could not accept this but ever since I started using medication from this clinic I never had a problem, I'm well I can feel it. When I obtained counseling I began to think positively because I realized that committing suicide was not the answer. I learned to accept this situation because there was nothing I could do to change it."

### **5.1.3 Normalizing Stories**

About 20 percent of the stories were of normalizing nature with one extremely normalizing. These

patients attempted to narrate and live a normal life in spite of an HIV diagnosis. They expressed no change in the way they used to perceive themselves before as compared to now and to be carrying on with the activities that were planned before the diagnosis.

This group was only comprised of male respondents of ages 27 and 28 and both in full-time jobs. One was married and the other still single but with steady girl friend. An important element that was noticed with these two respondents was that they had both disclosed their HIV positive status to their partners and both reported experiencing support and understanding from them.

A 27-year old man said:

"With me it's different, I don't believe that I'm going to die. There is nothing that can stop me from doing whatever I like to do. There is nothing that I may say has change in the way I used to see myself and in my physical make up. This situation has never made me feel bad or different in any way."

Another important aspect that may have contributed to their Normalizing style may have been their denial of personal responsibility for HIV infection. They felt that it was not their fault that they contracted the virus and that it may have been issues that were beyond their control. Generally, they seemed to be approaching the matter in a more "taking it like a man" kind of attitude and by telling their stories, they appeared to be getting more empowered and to reassure themselves towards positive thinking. The same respondent, 27, further complained:

"I can not tell you how I got this, I believe it's not that I'm careless you see. We Zulus do use traditional methods of healing and you find that the Inyanga will come to use his razor blade to the seven of you in the household and will carry on to the next family using the same razor blade. So, tell me, how many chances you have of contracting the virus through that? Therefore, I can't keep punishing myself by living my life in misery because basically, death does not come only in one fashion. We are all going to die, it's just a matter of time before it knocks on your door."

Another 28-year old woman expressed ambivalence about her future aspirations:

"I cannot tell because, you know, people change. I can say that I don't see a brighter future and it may happen that I find myself there, you never know."

#### **5.1.4 Creative story types**

About 20% of the sample used creative/transformational style to make sense of their HIV status. They would embrace many contradictions and tensions in their accounts rather than suppressing them. They appeared to imagine the future as a world of potential change. The following is an example from a 26-year old man's narrative:

"It came as a big shock to me, I could not accept this, but I'm well I can feel it, if I can find a job things will be much better. I used to wonder to myself whether it's wise to save money and don't get an answer. Those thoughts don't matter anymore because it doesn't mean I'm dying tomorrow because it may happen that as time goes on the government will give this a first preference and a cure will be discovered. So, I can say that my hopes have been cut off because maybe in two years I will still be alive when they find the cure."

#### **5.2 Turning points**

The turning points are the moments, in the respondents' narratives, when they experienced a shift or a major change in their narrative either for the good or for bad.

For 80% of the sample a turning point was experienced during initial HIV discovery when shock and disbelief suddenly taunted their lives. They then lived in constant fear, feeling secluded from the rest of the people due to their HIV status. This feeling caused these respondents to narrate their HIV discovery stories in a tragic manner. The development of somewhat tragic and creative story types became linked to the effects of social support on the respondents' narrative.

The entire sample experienced the CDC services to be a major positive turning point in their narrative. This is because they offered relief of physical symptoms, created better understanding of themselves and the virus through counselling and offered a sense of togetherness and hope. Support and understanding from families was experienced as a turning point by 20% of the sample and this seems to have helped them cope much better with their diagnosis. Another 20% decided to turn to religion for support and care, as they did not seem to get that from anywhere else. Because of these experiences, we begin to see the emergence of somewhat tragic and creative story types in that the respondents start to have mixed feelings about HIV discovery, which manifest themselves on their narrative.

Disclosing to their partners their HIV positivity began a negative turning point for another half of the sample when they experienced avoidance, rejection and subsequent break-up. This caused them further heartbreak because they lacked the necessary support from their loved ones. Rejection, betrayal and divided reaction from family members after disclosure left them feeling isolated and lacking social support. 40% of the sample vowed for secrecy for fear of being marginalised by their perceived ignorant and rejecting community members. This deprived them of social support when they needed it most. They were left to deal with their recent HIV discovery on their own because they could not disclose to others in the community. Therefore, the stories received from these individuals were of a purely tragic nature.

However, the turning points in the narratives outlined above did not appear to have any effect on the emergence of the Normalizing story types. These seemed to appear as coping mechanism employed by 20% of the sample and not linked to any outward influence.

### **5.3 Relationship between role players and turning points**

Earlier in this chapter, the turning points in stories were explored. The narratives were also examined to identify the roles played by particular participants in these turning points. For 100% of the sample CDC played a major role in their narratives in that it offered relief of physical symptoms, created

a better understanding of themselves and the virus and offered a sense of togetherness and hope. It helped create a shift in their narratives from tragic to somewhat tragic and at times to transformative stories.

70% of the sample experienced their partners as playing a role of ignorant and unsupportive victimizers which then allowed them (victims) a feeling of loneliness, social isolation and further heart break. This caused a turning point in their narratives in that they became more tragic than they may have been before disclosure. Another 70% of the sample was unable to utilise the family support network during this time of crisis and therefore became dis-empowered and unable to cope with their prevailing circumstances. This may have had a negative effect on their narratives in that the lack of support caused their narratives to be more tragic than they probably were before disclosure.

From this sample 30% of the respondents experienced their families as supportive and understanding. They were fortunate enough to experience substantial care, which helped them come to terms with their diagnosis and be strong to face it. This then may explain why their narrative shifted from tragic to somewhat tragic or creative.

For others in the sample (30%), their communities were narrated as stigmatisers, rejecters, mockers and victimizers. Because of this important fantasised role, the sufferers vowed secrecy concerning their diagnosis for fear of the above responses from the community after disclosure. This secrecy then allowed them to suffer social isolation and to lack social support in their lives. They would then create their own explanations of their present situations and inventing their coping mechanisms, which included Normalizing the impact of HIV discovery.

Only 20% experienced their churches as providers of support and care. These acted as turning points in their lives in that they allowed them a feeling of belonging, acceptance and understanding. This also caused a change in their narratives from tragic to somewhat tragic because of this experience of support.

## 5.4 Themes

Alongside types of stories, narratives were read to identify major themes spontaneously emerging. Most interviews testified to the traumatic nature of HIV discovery. Subjective experience of the trauma differed, however, and this was critical to its impact. Narrative analysis of participant's accounts revealed varied themes. Themes were identified and a content analysis of themes was performed.

See Table 3.

**TABLE 3.** Frequency of themes in narratives.

### THEME

	n	%
Hope due to CDC services	10	100
Secrecy	9	90
Job loss, depression	7	70
Social isolation	6	60
Loss of hope for the future	5	50
Support from family	4	40
Self blame	3	30
Requires employment to feel better	3	30
Turned to religion for support	2	20
Lost hope in developing self occupationally	2	20
Denial of emotional impact	2	20
Alienating self from responsibility for HIV infection	2	20

The following is the order according to which they were most common in the narratives:

- a) *Hope due to CDC services* – 100% of the respondents expressed a turning point in their perception of themselves, a better understanding of the virus and relief in their emotional and physical symptoms as a result of the services they received from the CDC. This feeling was expressed by the entire sample irrespective of age, gender, employment status, background, stage of illness and Story-type. A 23-year old woman said:

"I then decided to come to this clinic to seek help which I got. When I received this service my mother was very grateful that I managed to do something about my situation. After that I noticed I was picking up weight and returning to my normal state of health. Now, ever since I started using medication from this clinic I never had a problem, I'm well, I can feel it."

For some it offered a feeling of togetherness and hope. The following is from the above-cited narrative of a 26-year old single woman:

"When I came to this clinic I discovered that there are other people who are HIV positive and they are well, it's not only me and that means I can keep this with myself until the cure is discovered."

Even the respondents whose narratives were of a normalizing nature acknowledged the impact of this service e.g. one 27-year old man said, in his normalizing style:

"I believe that my life is still going to carry on as normal, there is nothing that can stop me from doing whatever I like to do more especially now that I'm under the doctor's treatment. There is nothing that I may say has changed in my physical make up because I get sick occasionally the same way I used to and it's much better now that I know what is wrong with me and what I can do about it according to doctor's orders."

b) *Secrecy for fear of mockery and rejection, stigmatization, change in relationships and causing pain to family.* This theme was found under the tragic story types.

About 90% of these respondents, both male and female, employed and unemployed expressed preferring to keep their newly discovered HIV status a secret from their families and the community because they expected the worst reaction from them as a then feared being demarcated and regarded as outcasts by their communities and loved ones. A 24-year-



old female complained :

"It's not easy to tell any other person about this situation, a friend or not. I don't see a need to tell them because you will only be helping them to have something to talk about and I don't believe there is anyone who enjoys being talked about. I did not wish for any other person to know because they will make fun of it."

Others feared causing more pain to the family after disclosure of HIV positive status :

"My problem was how I was going to break this news to my mother. She is sickly and so was afraid that maybe if I tell her this news she may be hurt so much that she would die or get affected one way or another and I would be responsible for her situation."

Some wanted to avoid perceived danger associated with disclosure. A 27-year-old man said:

"This may be a dangerous situation nowadays. For example, once in Durban there was a woman who came out in the open about her HIV status and people decided to kill her. This is then why it is not easy to disclose such a situation because you end up being taken as a stupid or careless person."

c) *Depression, anger, heart break and suicidal thoughts*

Respondents reporting these themes fell under the tragic story type. Narratives from this category were received only from female respondents. They received this news with great shock, sudden and violent disturbance in the usual way of things. They were caught unaware, unprotected as they heard the news. It blind-sided them, leaving them feeling disoriented. A 28-year old woman said:

"After I received this news I was devastated, very devastated that I did not know what to do about it. I became confused, could not think properly because I did not

know how I got this disease in the first place. It came as a shock to me and I had a problem accepting it. I suffered a lot of emotional pain and ill health and due to my ill health I lost my job because I could not go to work as often as I was expected to. I then stayed at home day in and day out with these disturbing thoughts on my mind. I considered committing suicide but when I thought about my children I decided not to do it."

d) *Aloneness, social isolation, loss of confidence in self and life and change in identity.*

This theme was associated with the theme about the patients' decision to conceal their diagnoses and was associated with tragic story types. Due to their secrecy, 60% of these patients lacked support from their families and loved ones when they needed it the most. They had to deal with this situation all by themselves.

A 28-year old woman complained :

"I was heart broken because it seemed like there was no one I could turn to, and everyone avoided me. I may say that my working future has been affected because no one will ever accept me again because for only one cough, they will say I'm unfit to work because I'm sick."

Changes in self-perception and identity crisis were experienced as a result. The above-cited narrative continued:

"I also don't regard myself as a normal human being because, as I told you, I worked for my relatives who chased me away for being sick. Just imagine how another employer would react if my own family rejects me. I seem to have lost that feeling that I am a healthy person who can support and care for others."

e) *Support from family*

Four of the respondents interviewed, 3 females and 1 male, expressed experiencing some form of support and understanding from some members of their families after disclosure. This seems to have empowered them to deal with this situation much better. A 27-year old female said:

"I then realized that I needed to talk to other people who care about this because it continued to hurt me inside without anyone to talk to. I eventually told one of my two younger twin sisters and then after some time I decided to tell my mother too but they did not have any problem, they even supported me with some money to come to this clinic. What helped me is that my parents accepted me when I told them about this situation, that is what was important to me."

A 26-year old female confessed to having disclosed her HIV positive status to her family, after two weeks of secrecy. She firstly disclosed her HIV positive status to her younger sister whom she felt would be the easiest to communicate with and from then on she felt empowered to tell the rest of the family.

"I did not know who to tell for a period of two weeks after which I decided to tell my younger sister though I was afraid of her reaction. It took her some time to say words of comfort to me, which made me strong enough to tell the father of my child. After sometime I also managed to tell my elder sister, who then told my mother, amazingly, my mother understood and accepted the situation and accepted me as I was."

f) *Self blame.*

Three of the respondents, 2 females and 1 male felt personally responsible for HIV infection. They believed this to be a result of their own ignorance and negligence. This theme was associated with the creative story types. A 26-year-old male said:

"To a certain extent I do blame myself because I think I could have taken safety precautions. I used to hear about this disease but never thought it real or something that could happen to me. Once you receive that diagnosis there is no turning back, so I believe that if I was careful I would have beaten this virus, now I have only myself to blame."

g) *Role of employment.*

The patients in this category believed that their condition was exacerbated by their unemployment status. They felt that they suffer more because unemployment adds to their already unstable emotional states. They also feel deprived physically as they require finance to consult the clinic for medication and to keep themselves well nurtured in their battle to stay alive. The following example was extracted from a 28-year old single woman's narrative:

"Right now it does not bother me that much but I must say that I believe I can deal with it much better if I can find a job. Employment is what can heal me emotionally at the moment. I just wish I would work so I'll be able to heal myself and bring my life back to normal. By healing myself I mean being able to obtain food and be able to pray and praise the Lord."

h) *Role of religion as support.*

Two of the respondents reported finding solace from their church congregations. They tended to lack trust in other human beings and believed that the only person they can trust in God. They also felt that the church was the only place from which they can obtain undivided support and sympathy: A 28-year-old woman said:

"I was heart broken because it seemed like there was no one I could turn to and everyone avoided me. I then decided to become a born-again Christian, which is where I was welcome, other Christians do help me here and there which is how

I survived up to date. I can say to you that there is only one person trust and that is God."

One respondent, 28-year old single woman, would try to believe she is cured due to her religious beliefs: virus is gone, but when these symptoms start showing I then realize that I'm still sick and

"As a believer, I pray a lot and after which I tend to believe that the feel down again."

i) *Lost hope in developing self occupationally and shattered future plans.*

Respondents in this category still strongly believed that their hopes to develop occupationally have been shattered. They felt that the employers would discriminate against them if they find out their HIV positive status. According to them, it may be hard to hide their status because they will have to miss work at times to attend clinic and employers would find out. This is how a male respondent, 27, expressed himself:

"I may say there is a disturbance somewhere somehow in my future plans because if I wish to change from my place of employment for a better job, usually they give you a form and in that form there is a column that requires you to state your condition of health. So it's not easy to mention that you have this virus because they will not employ you, no employer wants sick workers. Even if by miracle I get employed that will mean that every month I have a half-day when I have to come for my medication from this clinic. I'm not sure if the new employer will be pleased with that."

Some are even reluctant to apply for advertised posts due to their negative feelings about themselves. A 26-year old man said:

"I do experience some disturbance in my future plans because at times I do have dreams that one day I will be this or that but I then remember that I have this virus. This then means that I may not be able to reach that because this situation is disadvantageous for me in a lot of ways, for example one time I had applied for a job with the Correctional Services and with Addington Hospital. I attended all the interviews but when I learned that we were supposed to go for a blood test I withdrew my application because I knew I was HIV positive and which meant that I would not get the job. Generally I may say that this closes a lot of opportunities for you."

j) *Denial of emotional impact.*

This theme was associated with the Normalizing type of stories. They tried to deny that their HIV status has had any effect in their present emotional states, thus normalising its impact. A single 28-year-old man said:

"This situation has never made me feel bad about myself in any way. I still regard myself as a normal human being. Most people believe that when they get this they are going to die, with me it's different, I don't believe I'm going to die, I believe my life is still going to carry on as normal."

k) *Alienating self from responsibility to causality.*

One respondent attempted to invent some explanation leading to how he may have contracted the virus in a way that would show that it was not his fault. It was a situation that was beyond his control. The following is an example of a 27-year old man's expression:

"I can not tell you how I got this virus, I believe its not that I'm careless. You see, my brother, we Zulus do use traditional methods of healing and you find that the Inyanga will come to use his razor blade to the seven of you in the

household and will carry on to the next family using the same blade. So there are a lot of chances of contracting the virus through that."

## **5.5 Dimensions of the narratives**

In performing the analysis of narratives, various dimensions were examined in order to determine the respondent's sense of the following in their narratives: Self and identity, their body, relationships with their families, relationships with others and work related experiences. It was assumed that now that they have discovered their HIV positive status a change in their experiences of the above would be likely.

### **5.5.1 Self and Identity**

Analysis shows that 40% of the respondents interviewed experienced identity change or crises as a result of HIV discovery. This means that HIV infection caused them to view themselves differently from before. Some perceived themselves as worthless and abnormal individuals who were soon going to die. A 28-year old woman said:

"I also don't regard myself as a normal human being because if my own family rejected me imagine how other people will feel towards me. I seem to have lost that feeling that I am a healthy person who can support and care for others and to have lost hope in life in general. This situation has changed my life completely and there is nothing I can do about it."

The same percentage felt victimised, betrayed, vengeful towards the victimizers and used strong words to express their anger. The following is an example extracted from a 28-year old woman's narrative:

"The first thing that I thought when I discovered this was to get rid of my boyfriend

because I was very angry with him. I know that I got this virus from him because he was the only one I was seeing, no one else. Even my mother was hurt when she heard this because she knew how well behaved I was in matters of love affairs. I decided not to tell my boyfriend what was going on because I believe this was his fault. So he must discover on his own to towards his death."

Part of their reaction to being HIV positive was processing the cause of the infection. Some saw themselves as responsible, whereas other participants blamed others, exonerating themselves. A 26-year old man blamed himself for negligence and ignorance:

"To a certain extent I blame myself because I could have taken safety precautions. I used to hear about this disease but never thought it real or something that could happen to me. I don't blame anybody for this but I just blame myself for my ignorance, because we the youth around my place do not take this HIV seriously. We just never thought of it as something real or something that would happen to anyone of us, hence I took no safety precautions. In my relationship with my boyfriend we never even talked about HIV or Aids, it was something that did not exist in our vocabulary. So that ignorance is my, I can not blame anybody for it. Once you receive this diagnosis there is no turning back, so I believe that if I was careful I would have beaten this virus, now I have only myself to blame."

For 30% of the sample, their feelings about themselves were mixed the most having no confidence in themselves and low self-esteem. The rest saw no growth and development for themselves and a shift in the purpose of life e.g. a 23-year old woman said:

"It disturbs me a great deal but I feel right now the person who will be handling my life will be my mother. Whatever I do right now I do for her. Getting married and going back to school are things I eradicated from my mind because they are no longer for me."



### **5.5.2 Self-perceptions**

The stories were analysed to identify self-perceptions portrayed in the narratives. 70% of the sample regarded themselves as victims from the partners. The same percentage also voiced a fear of rejection and stigmatisation and therefore decided to keep the matter a secret. 50% felt alone, rejected and lacking support. For 30% of the sample, this situation was a result of their ignorance and negligence. They felt responsible for their present state of affairs that they could have taken safety precautions to avoid it.

Another 30% regarded themselves as outcasts or bad people from the community. They failed to see themselves as responsible citizens anymore. 20% voiced being hopeful because they discovered togetherness and are enjoying support from their families. Other percentages (10%) saw themselves as either victims of circumstances, strong to face virus, triumphant-survivors, denying responsibility for present scenario, called to repent for the Glory of God and ambivalent about their feelings concerning HIV positivity.

### **5.5.3 Physical condition**

HIV is generally known to have detrimental effect on the physical health of individual carriers. In response to HIV infection, people often feel unhealthy, unclean or dirty. This feeling is then aggravated by their experience of HIV related physical symptoms. However, in this sample 60% of these patients experienced themselves as physically healthy as a result of the CDC services they were receiving. A 26-year old married man said:

"...I then received some assistance from this clinic, they explained to me what to do. Firstly they informed me that there is medication that will help to boost my immune system like injections and tablets. Now ever since I started using the medication from this clinic I never had a problem, I'm well I can feel it. They also encouraged me not to miss my consultation appointments with the clinic and I did just that. I kept coming until my eyes would open and I could see again."

40% reported having lately gained more weight contrary to previous weight loss:

"When I received this service my mother was very grateful that I managed to do something about my situation. After that I noticed that I was picking up weight and returning to my normal state of health. At the beginning I noticed some changes like I lost my weight but after I've been coming here and accepted the situation I regained my weight."

20% of the sample reported having just been experiencing minor ailments, same as before. They tended not to view HIV as having any effect on their state of health and illness, with no difference in health from before. A 27-year old man said:

"I am basically not worried about anything physically because as you can see me now I have always been this weight from as far back as I can remember. Even when I weigh myself my weight does not signify any deficiency, today it may be 59, tomorrow 60, and so on, and my appetite is very stable."

Surprisingly in this sample, only small percentages (from 20% down) reported their experience of their bodies as sickly, tired, stressed, weak, losing weight, strong to face virus and worried about further physical symptoms.

#### **5.5.4 Work**

60% of the sample were unemployed and 40% of them feared being regarded as occupationally unfit and potentially losing jobs. They even avoided applying for advertised posts as they appeared to still be ignorant about new legislation concerning the employment of HIV positive people. They still believe that their HIV positive status allowed them to be disadvantaged occupationally and to have no confidence in their occupational future.

A 28-year-old man complained:

"I do experience some disturbance in my future plans because at times I do have dreams that one day I will be this and that but I then remember that I have this virus. This then means that I may not be able to reach that because this situation is disadvantageous for me in a lot of ways. For example, one time I had applied for a job with the Correctional Services and Addington Hospital. I attended all the interviews but when I learned that we were supposed to go for a blood test I withdrew my application because I knew I was HIV positive and which means that I wouldn't get the job. Generally, I may say that this closes a lot of opportunities for you."

20% only survived through part-time jobs. This was also because they feared applying formally for employment because they believed that their medical profile had a negative impact on the occupational future. They felt that their situation was hopeless because they needed formal employment to support their families and to help nourish themselves emotionally. The following is an example from a 46-year old woman's narrative:

"Right now I only live on part-time jobs like doing washing for rich people. I may say that my working future has been affected because no one will ever except me again because for only one cough, they will say I'm unfit to work because I'm sick. I just wish I could work so I'll be able to heal myself and bring my life back to normal. By healing myself I mean being able to obtain food and be strong to praise the Lord. It's hard to be sick and at the same time suffer with hunger, that's a serious problem."

20% of the sample was in full-time jobs. They reported occupational stagnation. They felt that HIV positivity allows them no opportunity for personal and occupational development. They also feared disclosing their HIV positive status to their work places for fear of losing their jobs.

"I may say there is a disturbance in my plans because if I wish to change from my place of employment for a better job they usually give you a form to fill in. In that form there is a column that requires you to state your condition of health. So, it's not easy to mention that

you have this virus because they will not employ you, no employer wants sick workers."

## **5.6 Role players**

The role players are the participants in the respondents' narratives whose effect contributes to the change in their stories of life one way or the other. These include the following:

### **5.6.1 Partner**

Sexual partners were the most important participants in narratives. For 70% of the respondents, their partners played a central role of ignorant and unsupportive victimizers. They were regarded as responsible for the respondents' present situation for which they eventually became avoiding and rejecting, leading to complete break up. A 28-year old man said:

" My girlfriend never took this seriously, she still could not acknowledge her sickness to be HIV related. I tried to encourage her to come to this clinic and I explained to her that we get some medication to help us in our situation but I couldn't get through to her. We then ended our relationship because we lacked understanding and despite my endeavours to bring her to the clinic she still did not agree."

These respondents were unlikely to experience the necessary support from their loved ones when they needed it most, which is why they felt vengeful towards their partners. This group (20%) decided not to inform their partners about their HIV discovery in a way to be punitive towards them, for them to discover about the HIV infection on their own. A 46-year old woman said:

"I decided not to tell my boyfriend because I believe this was his fault. So he must discover on his own or towards his death."

Only 10% of the sample reported experiencing support and understanding from their partners and

seemingly using it fruitfully. The following is an example from a 26-year old man's narrative:

" I only told my wife. She understood because when I explained to her she agreed to stay with me despite all this and I appreciated that because I do not know what I could have done without her support."

### **5.6.2 Family**

The family is the most important support network available to individuals, more especially during a crisis period. When individuals are able to utilise this support network they tend to become empowered to cope with their prevailing circumstances. For this sample, only 30% of the respondents experienced their families as understanding and supportive. They were the only people who were fortunate enough to experience substantial care, which helped them come to terms with their diagnosis and to be strong to face it. A 27-year old woman said:

"I eventually told one of my two younger sisters and then after some time I decided to tell my mother too but they did not have any problem. They even supported me with some money to come to this clinic. I may just say, generally, at home they treat me well because they knew what type of life the father of my children was living."

40% of the sample experienced divided response from their family members. This means that some family members understood and agreed to support them while other family members rejected them. These families then become insufficient support networks and not substantially fruitful to the patient. A 28-year old man said:

"My mother understood and managed to help me by encouraging me to come to this clinic with another aunt of mine who stays in Ashdown and who works here. My father does not say anything about this. When I told him he was very angry with me and blamed me for not taking safety precautions."

For the last 30% of the sample, their families were narrated as untrustworthy, unsupportive, rejecting, ignorant and stigmatising. These families were not told about HIV discovery for fear that they would aggravate instead of helping reduce, the emotional pain of HIV discovery among it's members. They were fantasised to enhance that feeling of nothingness and isolation that HIV discovery created. The following is an example from a 27-year old man's narrative:

"A friend or a member of the family must not know because when they do, the first thing that comes to their minds is death and so they will lose hope in me because of the fact that I have this disease. So you lose your place in the family when you are regarded as useless, good for nothing. They lose confidence in you because the first thing they know about you is that you will soon die."

### **5.6.3 Community**

The community is comprised of friends, peers, neighbours, role models and elders. These people form a potentially important framework to build or destroy a person's sense of self. For the entire sample in this it was anticipated that the community would respond negatively to the news of HIV infection. In this study, the community played an important role as fantasised others who would reject, victimise and stigmatise if they knew the person's HIV status. Therefore, for the respondents in this study, no support was received from the community members basically because of the failure to disclose HIV positivity to them. A 28-year old woman said:

" It's not safe to tell other people about this because you won't be accepted, they start treating you like dirt. They do not accept you with this kind of sickness, maybe they think you will infect them. So I don't want anyone to know, this will be the secret I will carry to my grave."

### **5.6.4 Church**

For a small percentage of the sample (20%), the church played an important role in their narrative. They expressed experiencing acceptance and understanding from their church members after

disclosure of HIV positive status. A 28-year old woman said:

"I then decided to become a born-again Christian which is where I was welcome. Other Christians do help me here and there which is how I survive up to date."

#### **5.6.5 Communicable Disease Clinic (CDC)**

For the entire sample, the CDC was viewed as the source of health, support, hope, relief of physical symptoms, offering a sense of togetherness and allowing patients to benefit from it's counselling services. A 26-year-old woman said:

"It was sad because I thought about committing suicide because by then I did not have much information about this disease. When I obtained counselling from this clinic I began and I realised that committing suicide was not the answer. I also discovered that there are other people who are HIV positive and they are well, it's not only me and that the medication can keep me well until the cure is discovered."

## Chapter 6

### Discussion

#### 6.1 Introduction

The main purpose of this study was to explore the illness narratives of people who are HIV positive in an attempt to examine the subjective experiences and quality of life of HIV positive individuals. The aims included the following:

- To assess the impact of social support on the psychological adjustment of these patients
- To determine the patients' fears and insecurities with regard to the present scenario
- To investigate the impact of HIV positive status on the patients' sense of self, identity, coping strategies and future aspirations and
- To assess the effect of the services received by these patients at the CDC on their experience of themselves physiologically and emotionally.

To be able to achieve this a narrative method was utilised to guide this research. This method provided a useful way of approaching the subjective aspects of human experience and, in this case, illness experience. The respondents in this research had an opportunity to tell, maybe for the first time, stories of their lives since discovery of HIV positivity, providing the researcher with the opportunity to investigate the major dimensions of the narratives of HIV/AIDS.



## 6.2 Major types of narratives

The analysis of the narratives suggests that for people like those in this study, the discovery of being HIV positive is a traumatic event. The trauma has been shown to include what Stevens and Doerr (1997), called the perceived threat to one's life and perceived responsibility for the death of others, the empty present and the bleak future, depression with attempted suicide and present suicidal ideation.

The majority of the sample described their experience of living with the virus in tragic and somewhat tragic type of narratives. The impact often took its toll in unrelenting misery, lack of support, social isolation, destabilisation of relationships, disturbances in self-identity and future aspirations. These patients expressed having to deal with these issues by themselves because they feared disclosure to their loved ones as, according to them, this would precipitate rejection and stigmatisation. This finding confirms what Alonzo and Reynolds (1995), asserted that individuals with HIV and AIDS are stigmatised because their illness is associated with deviant behaviour. Therefore, the respondents' internal representations led to an intense fear of any disclosure. Some participants even quoted as examples justifying their fears, incidents involving people being killed by community members after disclosure.

Miller et al (1986) suggest that such public responses generate the feeling of being unclean or dirty, such that these people may avoid discussing their diagnosis with others for fear of the anticipated response occurring. This, then, inhibits them from having access to necessary social support when they need it most. Rene et al. (1999) emphasise that individuals who lack social support tend to have lower levels of psychological well being and higher incidence of physical illness. Social support groups, can also provide a context which enables the stigmatised person to feel normal (Alonzo and Reynolds 1995).

Researchers and clinicians such as Stevens and Doerr (1997) have observed that rupturing events, like HIV discovery, can produce epiphanies. "Epiphanies are interactional moments that

leave marks on people's lives and have potential for creating transformational experiences". (p. 533).

Alongside tragic narratives, there were other narrative types. Narratives of less than half the sample were of a normalising nature. This group appeared to deny that this diagnosis effected a change in their original way of life. They refuse to believe that their lives have been shortened and their future disturbed in any way. As suggested by Ezzy (2000), they attempted to narrate and live a normal life in spite of an HIV diagnosis. Some of the respondents in this group would even consider themselves different from other human beings with regard to the manner in which this news affect the general public. It is assumed that they use denial as a defence mechanism in their attempt to come to terms with the trauma of HIV discovery.

The very telling of their stories, by people using denial, might have engaged them in what Crossley (1999) terms a process of self-empowerment. Therefore, their narratives may have become a way of dealing with traumatic events, particularly experiences of illness. This may have been a means to experience transformations in their lives in terms of values, spirituality and life priorities. Generally, this narrative could be seen as an attempt at adapting to their diagnosis by limiting the sense of vulnerability imposed upon them by the threat of a potentially terminal illness. This seemed to be working for them in so far as helping them maintain normal levels of psychological well being, which might have positive implications for, as suggested by Rene et al. (1999), their physical health.

A small percentage of the sample expressed themselves in a more creative and polyphonic style. This means that contradictions and more than one voice of self characterised their stories. They attempted to make sense of their scenario by acknowledging the emotional impact endured as a result of HIV positivity while at the same time expressing themes of hope and understanding. As suggested by Ezzy (2000), stories about HIV as a source of sadness through lost friends and careers, or of rejection were mixed with celebrations of the insight and self-understanding HIV had provided. Polyphonic illness narratives lead the people living with HIV

to believe that the future can no longer be colonised, in the sense that an HIV diagnosis removes the possibility that one's actions can control the future completely (Ibid).

### **6.3 Themes of narratives**

Themes appearing in the narratives were identified and organised by content analysis. Although this research was not specifically designed to investigate the effects of the CDC services on the lives of HIV positive patients, it is important to note that for most of the sample interviewed, these services seemed to induce a feeling of hope, as revealed in illness narratives, in that they brought about a relief in their emotional and physical symptoms. In interpreting the meaning of this finding, the possible influence of social desirability has to be considered, especially if the researcher was perceived as working for the clinic. If this was the case, it is possible that the respondents may have been tempted to narrate positive effects of the CDC services in their attempt to appear grateful and compliant to the health promotion program.

The next most prevalent theme in the narratives was that of secrecy which fell mostly under the tragic story type. The respondents, both males and females, working and unemployed expressed preferring to keep their newly discovered HIV status a secret from other people be it family, friends or community members. Their decision for secrecy was precipitated by a fear of rejection and stigmatisation that they expected from others should their HIV positive status be disclosed. This confirms Alonzo and Reynolds's (1995) suggestion that HIV positive individuals' condition is usually received with fear and avoidance, with patients often experiencing shunning, stigmatisation and mockery by family, friends, colleagues and associates (Alonzo and Reynolds, 1995). In this case it is important to note that stigmatisation and rejection were more of fantasised reactions than actually experienced.

The issue of stigmatisation and secrecy will be developed further later in this chapter as a separate heading.

Depression, anger, heartbreak, suicidal thoughts were grouped into one theme and was among the most common in the narratives. This theme was linked to the effects of their consultations with the CDC in that these symptoms were felt immediately after discovery of HIV status. Bartlett (1995) confirmed that patients with HIV do develop a depressive disorder at some time during the disease and this bears little relationship to any prior history of depression or to a family history of depression. This is because the news is so overwhelming for them such that it induces great shock and leaves them feeling disoriented.

The next most prevalent theme was that of expressions of aloneness, social isolation, loss of confidence in self and life and as a result changes in self-perception and identity crisis. This theme appears linked to the theme of secrecy because due to these patients' decision to conceal their diagnosis as, in Alonzo and Reynolds' (1995) terms, a defence against enacted stigma associated with the virus, they lacked social support from their families and loved ones. Their need for social support at this time became central to their adaptation process.

A theme of support from the family also appeared from a minority of those who disclosed the HIV status. According to Jager (1988), how a family reacts to learning of its member's HIV infection depends very considerably on the quality of the pre-morbid relationship. This would mean that these respondents who experienced support and understanding from their families may have achieved this through the prior closeness of their relationships with their families. This theme was differentiated by gender in that only female respondents confessed to this experience and mostly support was received firstly from their mothers and then extended to the rest of the family.

Rene et al. (1999) emphasise that individuals who contract HIV by means of high-risk behaviour not only need to deal with the fact that they have a life-changing illness but that they may have incurred the disease through their own actions. This knowledge can result in feelings of guilt, self-directed anger and self-blame. This may then be the reason why some of the

respondents expressed self-blame as one of the major themes in their narratives. They believed that their HIV positivity was a result of their own ignorance and negligence.

For men and women in the unemployed category, the role of employment was important in their present situation. They believed that their condition is exacerbated by their unemployment status. They acknowledged unemployment as an emotionally deranging factor in itself and therefore detrimental to their already existing unstable emotional status. Respondents in full-time jobs, two females and one male appeared to have lost hope in developing themselves occupationally and this situation to have shattered their future plans. They still believe that the employers will discriminate against them if they find out their HIV positive status. They seem not to be aware of the fact that this practice is now illegal in South Africa and in contravention of the Employment Equity Act of 1999. This theme fell under somewhat tragic story types.

The role of religion as support was also acknowledged by two of the female respondents in the narratives. They felt that their church congregations were the only places from which they could obtain undivided support and understanding. This appeared to have been helping them in their attempt to cope with their HIV positive diagnoses and to improve their quality of life. This finding may serve to underline Woods, Anton, Ironson and Kling's (1999), suggestion that religiosity is often viewed as crucial to both mental and physical health within the black community. From their research with African-American women, these authors discovered that religious behaviour may serve as a marker for social support. According to them, increased church attendance may bring the HIV positive individuals together with peers and family providing added opportunities for maintaining positive health behaviours (e.g. adherence to medications and physician visits) which could mediate for immune system status.

A theme of denial of emotional impact was cited and associated with the normalising story types. These respondents felt that their HIV positive status had no negative impact on their present day to day activities and that their future plans were still in place as previously organised. Denial may be an unhealthy defence mechanism but it seems to have been working

for these respondents who appeared to use the interviews to endorse their normalising styles. The meaning of themes will be discussed fully in the "major questions from rationale" later in this chapter.

#### **6.4 Stigma and secrecy**

Stigma appears to be a major issue in HIV infection. In this research, it seemed to be more of a fantasised reaction in narratives of most people rather than an actual experience. This means that the people who were interviewed in this study confirmed Miller et al.'s (1986) suggestion that most patients avoid disclosing their HIV positive status for fear of the anticipated stigmatisation occurring.

Their internal representations of others as rejecting and stigmatising to persons infected with HIV caused them to conclude that the same will happen to them should their HIV status be disclosed. They then decided to keep their HIV positive status a secret because they are aware of the fact that, as Alonzo and Reynolds (1995) put it, HIV infection is regarded as a product of deviant behaviour and allows them to be treated with avoidance by others. This fantasised stigmatisation by the sample in this study begins from as close to the individuals as are their families and extends to all other support network available to them e.g. work and community members.

Fleming et al. (1988) maintains that HIV infection creates a family disruption that is felt at all levels of individual and collective life within the family. It became apparent in this research that HIV positive patients are aware of this and therefore fear being regarded as responsible for such disruption. They fear losing their respectful places in the family including their credibility as role models and a disappointment to their parents. Such constant fear therefore, leaves them with no option but to keep their HIV positive diagnosis a secret from their families.

This then has negative implications for them in that as a result of their secrecy, they fail to experience the necessary support and care due to them from their families. It is also important to acknowledge that, in this sample, a few respondents reported, despite their fears, having disclosed their diagnoses to their families and having experienced support and understanding from them. Families were shocked when they first heard this news but later understood and offered care. Only one of those who disclosed to their families reported actually experiencing stigmatisation and rejection which suggests the fantasised nature of this reaction by most of the respondents. Nevertheless, Jager (1988) suggests that after HIV disclosure, whether the family accepts or rejects the person is irrelevant, disruption will be experienced. This explains then that it may not only be an issue of acceptance or rejection but also one of avoiding being labelled as responsible for family destruction that may lead to secrecy.

The community is composed of neighbours, friends, relatives, elders and others. These are the people with whom each individual identifies through constant contact and collaboration. In this research, the entire sample interviewed regarded the community members as fantasised stigmatising others. The fact that community members become narrated as stigmatising others shows that awareness of disgust, with which HIV infection is received within community circles, existed with the patients concerned. It may then explain why they prefer to remain anonymous, as they believe they may be regarded as naïve, careless and dangerous. Alonzo and Reynolds (1995) suggest that there may be negative effects of concealing one's diagnosis from others. According to them, it is emotionally exhausting in that the stress of living a double life may be a heavily felt burden. To this suggestion by Alonzo and Reynolds's (1995), findings of this research confirm that the HIV positive patients prefer that burden rather than being stigmatised. They are further tempted, as part of their narrative, to construct some explanation as to how they contracted the virus thereby reducing personal responsibility for infection.

Work related aspects of HIV narratives include the belief that their jobs would be at stake if their employers found out about their HIV positive status. They also feared contesting for better employment as this may lead to disclosure of HIV infection and as a result to stigmatisation

and expulsion. Those who were unemployed also shared that same feeling with the rest. They felt that there is no future for them in the employment sector due to their HIV status.

These narrative constructs stand in contrast to recent developments concerning the employment of people with HIV in accordance with the Employment Equity Act of 1999, which stipulates that it is illegal to discriminate people in the employment sector based on their HIV status. They still felt that most employers are not willing to bear the costs of employing HIV positive people hence they resort to conducting HIV testing before employment. They still felt excluded and treated differently in this sphere too. This may then mean that the load they have been subjected to when they received their diagnosis is so heavy that it may be hard for them to keep an open mind regarding recent developments about HIV/AIDS epidemic. All they may be concerned about right now is what this infection means to them.

### **6.5 Life and Narrative**

The literature on narratives and narrative analysis debates the relationship between life experiences and the narrative created by the respondents. In this study, the respondents' internal representation of HIV infection seemed to guide their narratives rather than necessarily being based on actual life experiences.

According to Coste (1989) a narrative is an act of communication in which the imparting of the transitive view of self and the world is the effect of the message produced. This means that narrative does not necessarily have to be the result of the actual experience but can be a product of the combination of the view of self and the world. That is, if people view themselves negatively in reaction to the outside world that is enough to warrant a self-deprecating narrative. For example, it became evident that for the sample of the study a construction of the negative implications of HIV infection existed even before these were experienced and therefore determined the negative nature of their narratives. They were then destined to think the worst of themselves in relation to others but based on vicarious experience by others. These



findings underline Chidwick and Borril's (1996) suggestion that exposure to peer group members who are unwell and who died of HIV tend to have deleterious effect on the psychological well being of recently diagnosed individuals.

Furthermore, it was noted that for most of the sample their narratives became a construction to deal with life experience. Because of the space for personal explanation and detail that the narrative method allows the respondent, as noted by Katzenellenbogen et al (1991), the stories that people tell enable them to act with a view of shaping and protecting their own future. In addition, Ezzy (2000) explores the moral and public health implication of these narrative forms. He quotes a study by Hassim (1994) that examines the public health implications of the narratives of female intravenous drug users. This study discovered that "dope fiend" narratives deny these women agency and dignity, making it more difficult for them to take responsibility for their actions and participate in public health prevention campaigns. The same seems to happen with the kind of narratives told in this study, in that they deny these respondents the opportunity to experience necessary support for them to be able to deal with their diagnoses better. It also impacts on their ability to engage in public health programs such as HIV/AIDS education campaigns for which they can be useful components. Alonzo and Reynolds (1995) suggest that the HIV positive concealing individual may be highly motivated to sustain participation in social and occupation activities so as not to let others know or be suspicious of his/her status.

## **6.6 The quality of life of people who are HIV positive**

One of the motivations of this study was to explore quality of life of HIV positive individuals. Allison et al. (1997) suggest that people with chronic illness such as HIV related illness usually have a worse feeling of well being than other individuals. This research has shown that people who are HIV positive tend to respond negatively towards themselves and expect the worst from others through stigma and discrimination. As a contribution to the emerging importance of quality of life for people with chronic illness, this study attempted to explore the effects of

being HIV positive on various dimensions to quality of life of people with HIV. According to Bush et al. (1995) these dimensions include the social role function, the psychological well being and the physical function.

Regarding the social dimension of functioning, a central finding was that their avoidance of disclosure, while being utilised as a form of self-protection, deprives them of the necessary social support. Their social role function appears to have suffered in that the HIV positive persons, for fear of discovery of HIV infection by other community members, avoid engagement in normative social interactions.

Psychologically, Alonzo and Reynolds (1995) emphasise that concealing the diagnosis may be emotionally exhausting in that the stress of living a double life is a heavily felt burden for the HIV infected individual. It usually manifest itself in maladaptive interpersonal relations e.g. withdrawal, dysfunctional sexual life (fear of causing death to others versus fear of disclosure) and impacts negatively on family dynamics (family members may find it hard to understand depression with unidentified source).

With respect to the physical dimension, the sample selected for this study was still in the asymptomatic stage of HIV infection. It was therefore hard to assess their quality of life in the physical domain, although reports suggested a fairly general state of physical well being. The CDC services seem to have played a major role in helping them adapt to minor ailments that may impact negatively on their quality of life. This suggests the important role of the health care and the counselling services on the quality of life of HIV positive individuals. These services seem to help install a sense of hope and to rid them of negative self-evaluations.

### **6.7 Implications of findings**

What can we conclude from the above findings? Firstly, one of the most important findings of this study is the element of stigma and blame that is attached to the disease and its victims. It

appears that HIV infection is still received, by the communities of the participants in this study, with shock, avoidance and stigmatisation based on the lack of understanding of the disease itself. As a result of this, the diagnosed individuals decide to avoid the significant costs of being labelled as different or deviant, especially because the deviance is negative. They then keep their diagnosis a secret from others as a desperate attempt to protect themselves from stigmatisation and rejection. Leask, Elford, Bor, Miller and Johnson (1997) stress that the persistent stigma associated with HIV and AIDS in society is likely to inhibit disclosure because of its association with deviant activities.

The above finding has negative implications for the HIV positive individuals because not telling others about ones HIV diagnosis may decrease opportunities for social support, which in turn buffers the anxiety and stress associated with ill health. Social support has been acknowledged as fundamental in HIV infection in that it helps the victims feel understood and accepted which in turn enhances their desire to live. Furthermore, concealing one's diagnosis has obviously negative implications for public health in that these individuals may fail to participate in health promotion programs and may continue to engage in sexually undesirable behaviours thereby putting others at risk of infection.

Secondly, this study's most prevalent tragic manner in which the respondents told their stories of HIV discovery signifies the negative impact this disease has on their quality of life. The traumatic element of receiving a life-threatening diagnosis appears to have been a devastating blow and potentially overwhelming for these respondents. The realisation of HIV infection seems to have effected a drastic change in their lives such that they experience themselves as different from others in the community.

Lastly, it is interesting to note the positive impact the primary health care services have on HIV infected individuals and in HIV related illnesses. The respondents in this study narrate an improvement in their health as a result of the services they receive from Communicable Disease Clinic. This is the evidence for effectiveness of the primary health care services on the

HIV positive patients. The medical treatment and counselling services offered at this clinic appear to restore a sense of hope for the future and to help improve their quality of life. The patients who do not disclose their HIV status to others may benefit from counselling which focuses on issues of psychological adjustment, isolation and support (Leask et al, 1997). Therefore, some understanding of the patterns of disclosure is imperative if counsellors are to promote healthy approaches to coping in the lives of people with HIV.

These conclusions are entirely consistent with a narrative or storied approach towards the study of illness, which seeks to appreciate more fully the integration between individuals, stories and cultures in which they live. This means that HIV positive individuals who participated in this research attempt to define themselves in relation to a community of which they form a constituent part. The language most communities use regarding HIV infection is not neutral (Evian, 1995). It influences our perceptions both of the disease and of its carriers. There is a very real danger that the mythology and terminology used about HIV/AIDS may make it harder for people to take intelligent precautions against its spread. It is, Therefore, evident that we need not treat just the patients, and not just the disease, but the society as a whole when we look at HIV/AIDS.

### **6.8 Limitations of the present study**

Caution is required in generalising from the findings of this qualitative study. The sample that was chosen to participate in this study was very specific. The experiences of this black, low-income sample can not be taken as representative of other groups. Therefore, future research into the area needs to explore a larger and more diverse sample in order to maximise generalizability.

In addition, the respondents who participated in this research were generally in the asymptomatic stage. Therefore, their experience may be different from others whose infection has progressed to display symptoms. Long-term follow-up on the assessment of the subjective experience of living with HIV at different stages of illness is also recommended. Longitudinal

follow-up would also be interesting to study the effects of various narrative styles on longer-term coping and quality of life e.g. the impact of denial.

Also included in the limitations of this study is the effect of social desirability. It is possible that the respondents may have perceived the researcher as working for the clinic which might influence the validity of the findings of this study. To counteract this, it is recommended that future researchers make use of diverse research settings.

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# APPENDIX

## CONSENT FORM

Participant's age \_\_\_\_\_ Date of birth \_\_\_\_\_

In a study of the subjective experiences of people with HIV

1. I hereby authorize Simphiwe Templeton Sinkoyi, a registered Masters student in the Faculty of Social Science of the University of Natal, to gather information from me concerning my experiences of living with the virus.

I have freely and voluntarily consented to participate in this study with no coercion, psychological or otherwise, to elicit my participation.

My participation will involve answering interview questions and giving background information.

2. There is no physical and psychological risks involved in any of this work. I have been assured that I am free to refuse to discuss any matters that cause me discomfort or that I experience as an invasion of my privacy.
3. I may terminate my participation in this study at any time.
4. I understand the statement, submitted to me by the investigator, as to how confidentiality will be maintained.

\_\_\_\_\_  
Participant's signature

\_\_\_\_\_  
Date