

**HIV AND METAPHOR:
AN IMAGINATIVE RESPONSE TO ILLNESS**

THESIS

submitted in fulfilment of the
requirements for the Degree of

MASTER OF ARTS

in the Department of Psychology
Rhodes University
Grahamstown, South Africa

by

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May 1998

ACKNOWLEDGEMENTS

- My sincerest gratitude to my supervisor - Carol Hammond - for her invaluable assistance and her accessibility, interest, encouragement and support.
- To my parents Richard and Helen - for their love and support - and to my brother Michael for his valuable comments and constructive criticism.
- To Michelle Crowley for her guidance in the initial stages of this research and to Maureen Stewart for her assistance in proof - reading.
- Finally, to Sarah, Diane, Pat, Jan, Mercy & David. Thank you for so willingly sharing your stories and your time.

The financial assistance of the Centre for Science Development (HSRC, South Africa) towards this research is hereby acknowledged. Opinions expressed and conclusions arrived at, are those of the author and are not necessarily to be attributed to the Centre for Science Development.

To my dear Larry - for everything

The appearance does not hide the essence, it reveals it; it is the essence

(Sartre)

It is the imagination that distinguishes one man's suffering from another... the image which holds both the promise and the destruction, the escape and the rebirth...

(Anon)

ABSTRACT

The medical model has been criticised for its failure to attend to individuals' experience of illness and the meaning they attribute to illness. HIV/AIDS has challenged its adequacy and brought the question of meaning in illness into sharp focus. This study aimed to understand what it means to live with HIV by exploring the fantasies, images and metaphors that make up the depth of such an experience. Phenomenology was deemed the appropriate approach, as it assigns epistemological significance to metaphor and ontological primacy to the lifeworld. An interview guide was fashioned from existing phenomenological literature and in-depth interviews were conducted with eight HIV-infected individuals. Five protocols were selected to constitute the study. In addition, an audio tape recording of one individual's metaphorical dialogue with HIV was obtained and transcribed. The three protocols with the richest content of imagery and metaphor were subjected to phenomenological explication. The remaining two protocols were used to support and clarify emergent meaning. A phenomenological explication of the data revealed a number of salient metaphors and themes. Upon being diagnosed with HIV, individuals were confronted with a socially and institutionally prescribed understanding of the disease; HIV as synonymous with AIDS and immediate death, HIV as sexual deviance, and HIV as myth. These metaphors influenced their conceptualisation and handling of HIV. Individual embodied metaphors included: embodying a heart of stone to live with HIV and perceiving HIV as a punishment from God, a demon from the Devil, a death sentence and a torture. Affectively, the experience of HIV was constituted as fear of physical disfigurement and exposure, anxiety, vulnerability, anger, betrayal, injustice and isolation. In a process of resolution and transformation, individuals imbibed positive metaphors with which to continue living with HIV. In order to cope with HIV, individuals seemed to negotiate a metaphorical space in which to dwell with their virus. This entailed establishing some form of dialogue with HIV or a Higher Power. This study revealed that metaphorical thinking about HIV/AIDS has a powerful impact on individuals' embodiment of their world. Metaphor is also an effective means of conveying and eliciting meaning in the experience of illness. Based upon these findings, it was suggested that metaphor be a prime focus for future research endeavours.

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CHAPTER ONE

INTRODUCTION

The challenge of AIDS, demands of us a return to the caring which was so much commoner when we were as impotent in the face of most illness, as we are today with AIDS. (Hull, cit. in Ray, 1989)

This study seeks to understand what it means to live with HIV (Human Immunodeficiency Virus), by exploring the fantasies and images that make up the depth of such an experience. The stance adopted in this research is that metaphor provides a point of entry into the life world of those experiencing illness (Czechmeister, 1994), as well as exerting a profound impact upon the way in which individuals construct an understanding of and deal with illness (Stibbe, 1996). Given its attention to the way in which the imaginal psyche responds to the reality of illness (HIV), this study invites an essentially imaginative response to illness.

The phenomenon of illness has hitherto been understood in terms of a biomedical framework. However, there is an apparent air of disenchantment in the literature with regard to the legacy of the scientific/biomedical tradition and the influence it exerts upon the way illness is perceived and managed. Such a concern is manifest in much writing (Boss, 1979; Bjork, 1983; Kirmayer, 1988, 1992; Kleinman, 1988; Kolbe, 1996; Lupton, 1994; Stein, 1990) which speaks of the tendency of biomedicine to ignore individuals' experience of illness and the meaning they attribute to illness. The limitations of the biomedical model have come into sharp focus since the advent of HIV/AIDS¹. Since biomedicine offers no solution to HIV/AIDS, there is an increasing recognition of the need for alternative ways in which to attend to and deal with the illness. Critics of the biomedical model suggest the need for a return to the lifeworld of those experiencing illness (Kleinman, 1988; Kirmayer, 1988, 1992; Kolbe, 1996) and propose that metaphor is a valuable approach to understanding the experiential lived world of the patient (Czechmeister, 1994; Grothmarnat, 1992).

¹ HIV/AIDS is used where no clear distinction is made between HIV- infection and AIDS (Acquired Immune Deficiency Syndrome), and being HIV positive and suffering from full blown AIDS.

1.1 Phenomenology as an alternative approach to illness

The stance adopted in this research is antithetical to conventional biomedical notions of illness in that it is primarily concerned with the meaning inherent in individual experiences of illness. This study situates itself within an existential-phenomenological approach to understanding illness, assigning pre-eminence to the study of metaphor as a valuable way of understanding the experiential lived world of the patient. Phenomenology provides an invaluable approach to the phenomenon of illness because it seeks to understand such an experience by participating in the lived world of the individual. Because it affords epistemological and ontological primacy to metaphor (Brooke, 1991), phenomenology also provides a means of understanding how metaphor is embodied and lived out in illness.

1.2 What is metaphor?

Many writers, including Czechmeister (1994), Grothmarnat (1992) and Hillman (1977; 1990) would agree that one way of accessing the depth of meaning in illness is by looking at the metaphors, the fantasies and images that mediate such an experience. Most studies dealing with metaphor and illness have been informed by the theoretical orientation of Lakoff & Johnson (1980) who articulate the pervasive nature of metaphor in everyday life. Working within the spirit of association and analogy, metaphor is a way of understanding and experiencing one kind of thing in terms of another. Metaphor may be viewed as 'a motion, as a change, as a carrying over of the sense or meaning of one reality to another' (Romanyshyn, 1975, p.451). Indeed Wheelwright (1962) mentions that etymologically the word implies motion (phora) that is also change (meta). A simple example of metaphor might be describing love as magic, or argument as war (Lakoff & Johnson, 1980).

Although metaphors may readily be thought of as imaginative expressions they are also lived realities that profoundly influence and shape experience. Such an idea is extrapolated in the writing of Romanyshyn (1975; 1982) and Hillman (1977) who expound upon the ontological import of metaphor; in other words, how metaphor is embodied and lived. Because this thesis

is concerned with the phenomenon of illness (HIV), special attention is given to the way in which metaphor affects individuals' understanding and experience of HIV.

1.3 How can metaphor affect patients?

There are a number of ways in which metaphor can affect individuals suffering from illness. This thesis is predominantly concerned with two main issues regarding the role of metaphor in illness.

Firstly, metaphor acts as a bridging device, mediating experience in a meaningful way. Any experience of chronic illness is accompanied by extreme feelings and HIV/AIDS in particular affects the psyche in a profound way, ultimately calling forth the reality of death and finitude. Effectively communicating such experience is often a difficult task since many of these feelings of illness and pain remain largely intangible to those not directly experiencing HIV/AIDS. The need persists however, for patients and caregivers to seek and communicate meaning and feeling upon confronting the reality of human mortality. In this instance, it is argued that metaphor provides a way of discovering and translating meaning in the face of such an encounter. According to Lupton (1994), 'individuals who have experienced illness or disease have often reverted to metaphorical discourse to conceptualize to themselves and to others their experience'(p.54).

Metaphor is perceived as a vehicle for carrying, mobilizing and expressing the inchoate nature of painful and intense immediate experience (Cox & Theilgaard, 1987; Murray, 1975; Siegalman, 1990), giving 'affective expression to experiences relating to matters of stigma, uncertainty, fear and pain' (Radley, 1993, p.120). In effect, metaphor not only allows patients to communicate meaning more easily but also provides others with a certain knowledge of what it means for the patient to be ill. This is important in the case of HIV/AIDS because the illness is often responded to with fear and uncertainty (Brandt, 1988) and many HIV/AIDS sufferers are loathe to share their experience with others. In this instance, it is hoped that metaphor will provide a point of entry into each individual's experiential world, as well as mediating the

experience of HIV in a rich and meaningful way.

Secondly, metaphor impacts upon the way in which individuals experience illness. Stibbe (1996) emphasises that metaphorical thinking about illness affects the feelings, reasoning and actions of patients and health practitioners and may therefore have an impact upon the quality of life and/or progression of illness. Some metaphors may have a positive and transformative impact upon patients and effect a new and positive modality of being. Grothmarnat (1992) points out that metaphor can potentially facilitate change and create new meanings and behaviours. On the other hand, metaphor may have a negative impact upon patients and induce feelings of shame and fear. For example, metaphors such as HIV/AIDS as punishment, judgement and death sentence are common ways of understanding the disease (Sontag, 1989; Norton et al., 1990).

What is considered important in this study is the way in which metaphorical thinking about illness impacts upon the way individuals constitute their worlds. For example, an HIV sufferer may think of his/her illness metaphorically, as a punishment or a death sentence. The world of the HIV sufferer may be transformed when their illness is contextualised through these metaphors. What impact does this way of imagining HIV exert on one's relationship to others, to one's body and to one's world? By exploring the impact of metaphor in this way, this study hopes to provide a psychologically relevant and meaningful response to the phenomenon of illness.

An understanding of the way in which metaphor impacts upon the experience of HIV may have important implications for doctor-patient interactions and the therapeutic relationship. An awareness of which metaphors exert a positive and transformative impact upon patients can be an important tool for effecting positive change in patients' health (Carter, 1989; Huckins, 1992). A familiarity with metaphor in general can also help the therapist better understand clients, communicate more effectively with them, and intervene more potently (Mays, 1990), and as Carter (1989) aptly puts it, 'may contribute to ways patients and caregivers build and come to share worlds of compassion, meaning and significance' (p.7).

1.4 Structure of thesis

The structure of this thesis is as follows: The literature review, which constitutes the second chapter of this research, is primarily concerned with establishing an alternative approach to the phenomenon of illness. The first section entitled *HIV/AIDS, Metaphor and Meaning*, critically addresses the biomedical and socio-cultural frameworks through which HIV/AIDS has come to be understood and managed. Section two, entitled *Recapturing imaginative and immediate experience*, concentrates on establishing an alternative ontological and epistemological basis from which to explore illness, and HIV in particular. This is done by attending to the metaphorical grounding of existence and by conceptualising the body as a meaningful and an imaginative subjectivity. Section three, *Accessing the embodied metaphor*, addresses those areas of human existence which need to be explored if the embodied metaphor is to be accessed. It too seeks to establish and pose questions with which to proceed with the phenomenological inquiry.

In Chapter Three the methodological parameters of the research are addressed. The phenomenological method is firstly discussed in terms of its appropriateness for inquiring into this field of study. Thereafter the way in which this method was rigorously and systematically applied to the question of concern is addressed. The results that emerge from this study are documented in Chapter Four. In order to illustrate the methodological procedure adopted, one participant's explicatory process is fully documented up to and including her case synopsis. The implications of the results are discussed in Chapter Five. Where appropriate, direct excerpts of participants' experience are presented to relay the immediacy of experience, and in support of key considerations. Chapter Five concludes with an evaluation of the approach assumed in this research as well as suggestions for further research.

CHAPTER TWO

LITERATURE REVIEW

Modern man is, in general, an awkward visitor of the sick, unable to participate in the “lived universe” of the patient, because he has lost familiarity with, and therefore the ability to converse about, illness and death. (Czechmeister, 1994, p.1230).

1. HIV/AIDS, METAPHOR AND MEANING

HIV/AIDS poses a significant challenge to our modern epoch. The United Nations informs us that the number of people infected with HIV has been underestimated. Figures reveal that 1 in every 100 sexually active adults between 15 and 49 harbours HIV (Anon., 1997/1998). While in the USA the vast proportion of people living with HIV are homosexual men and/or drug abusers, in Africa, HIV is predominantly heterosexually transmitted. Transmission of the HIV virus includes sexual contact, infected blood, intravenous drugs and perinatal infection from mother to foetus or infant. HIV related deaths have the greatest impact on young and middle aged adults particularly racial and ethnic minorities, namely, African Americans and Hispanics (Centre for Disease Control, 1996; RxHealth, 1996). Statistics show that women are at a high risk for HIV- infection and women account for an increasing proportion of newly reported AIDS cases (Centre for Disease Control, 1996; Cochran & Mays, 1989).

As the severity of the pandemic continues to intensify, more and more people are confronted with the inescapable reality of human mortality. There is currently no curative treatment and no vaccine for AIDS. Brandt (1988) comments that ‘AIDS constitutes a public-health crisis of global dimensions, a sad but powerful reminder of our relative inability to alter the nature of the biological world’ (p.414). It has come to be known as ‘a disease constituting a natural experiment in how societies respond to disability, dependence, fear and death’ (Brandt, 1988, p.414). It has been said that ‘AIDS marks a turning point in current attitudes toward illness and medicine, as well as toward sexuality and toward catastrophe’ (Sontag, 1989, p.72). It has

even been termed a 'painful soul condition of culture' (Sardello, 1988, p.16).

If one is to ask the question, what is HIV/AIDS?, it is necessary to examine the metaphorical frameworks through which such a disease has come to be understood and managed. HIV/AIDS has essentially come to be conceptualised and dealt with through the metaphorical framework of the biomedical model. However, an epidemic as severe as HIV/AIDS has also come to be largely constructed through a variety of social/cultural metaphors. According to Levin (1987b), 'disease, especially life-threatening disease, is the locus of collision for individual and collective, social and biological, material and nonmaterial, sacred and profane imperatives' (p.171). Levin (1987b) adds that 'disease that is perceived as uncontrollable, beyond the technological range of our culture's medicine, will likely become the subject of a significant discourse framed in nonrational terms' (p.169). The fantasies surrounding the origin, definition and interpretation of HIV/AIDS, bear testament to biomedicine's inability to gain mastery over the disease. Both biomedical and socio-cultural metaphors yield a decisive impact upon the way in which HIV/AIDS is meaningfully construed.

1.1 Scientific and biomedical understandings of illness

Our principle epistemological framework for understanding and dealing with illness is Western science. The entire edifice of modern medicine rests upon what Bjork (1983) refers to as 'an outdated world view based on a mechanistic, Cartesian-Newtonian science' (p.139). Modern medicine is little concerned with the existential meaning of most physical illness. According to Boss (1979), 'physicians have from time immemorial considered their primary objective to be mastery over at least the disease of man' (p.20). This translates into a decisive preoccupation with conceptualising disease in terms of technological facts, and focusing on the cause, prevention and cure of disease. The human body is envisioned as a physical object which must be scrutinised, manipulated and corrected via technological means. The meaning individuals attribute to illness is seldom recognised, and the emotional import of illness is obscured by medical imperatives. The way in which biomedicine continues to conceptualise

and manage disease has been challenged. Some refer to the inadequacy of the medical model as a “crisis” (Bjork, 1983; Kolbe, 1996) in medicine.

In order to understand the biomedical approach to illness, it is necessary to explore the ontological and epistemological framework from whence it emanates. Such an examination allows an understanding of how science harbours a vision which dispenses with the body as ground of experience. By removing itself from the world in which experience immediately takes place, science is an expression of a world view that constructs rather than discovers its reality. The world of appearance, of meaning, of imaginative and immediate reality, is supplanted by a world of empirical fact and bland literalism.

1.1.1 Historical overview

The biomedical model is grounded in a natural-scientific philosophy. The story of the natural-scientific view of human being, is the story of man/woman’s gradual severance from his/her authentic ground of existence. It is the story of his/her estrangement from the earth and his/her retreat from the body. Romanyshyn (1973) writes that ‘science broke the world apart and created for itself a special world, a world more real than that experienced world of appearance. Now only science describes the real’ (p.198). The modern technocrat ordinarily imagines a world which is ontologically severed from human existence. So too does he/she assume the human body to be radically separate from the omniscient mind. This tendency to advocate incompatible duality is an embedded way of seeing. This is the attitude we have inherited. It is an attitude which devalues the world of appearance, a ‘falling asleep’ (Heidegger, 1967) to the world in which we live.

Romanyshyn (1973, 1982) illustrates the birth of this new attitude, this new way of seeing nature and man, by way of the Copernican Revolution. In 1543 Copernicus’s treatise dealing with the revolution of the earth around the sun was published. The Copernican Revolution at its foundations, was a transformation of the basic attitude towards things. To prove that the earth in fact circled the sun, Copernicus had to move outside himself and beyond himself. He

had to imaginatively stand on the sun. As Romanyshyn (1982) explains, Copernicus had to 'disregard the appearance of things, and in place of the *experience* of the earth as the stable and central ground of humanity's place in the heavens he must substitute an *idea* of it' (p.20). Therefore, 'in giving up the ground and substituting a new one, Copernicus established the possibility of constructing a world beyond the world of appearance' (Romanyshyn, 1973, p.193). In effect, Copernicus was able to 'temporarily disregard the appearance of things and so to dispense with the living body as ground of knowledge' (Romanyshyn, 1982, p.21). According to Romanyshyn (1973, p.192), the Copernican Revolution was:

a falling asleep to the original and primary reference to things, a forgetting of things in their immediate and original givenness, a passing over and beyond the thing as it is given to us in its appearance to the thing as it is constituted in advance by science.

The suspension of man/woman's immediate presence to the world was later to be expressed in the works of Versalius, Galileo, Descartes, and Newton, the pioneers of scientific thought. Descartes's distinction between *res cogitans* and *res extensa* located human consciousness exclusively in the mind, an immaterial, internal "location", radically separate from the natural, material world of which the body is part (Brooke, 1991). Kruger (1988) comments that 'man came to lose his bodily, incarnated existence and distantiated himself from both his own body and from the material world and to look upon both as mere objects or brute facts' (p.6). The body which Copernicus left behind in order to move the earth became the body of anatomy and physiology¹. It became the corpse whose life was 'no longer understood in terms of the world but rather in terms of the mechanisms of the physiological body' (Romanyshyn, 1982, p.21). Van den Berg (1972a) writes that in order to do science one must abandon one's body. This methodic distrust of experienced appearance is the power of modern science and the nourishing soil of modern psychology.

¹ In 1543 Vesalius's book on the fabric of the human body appeared. This served to inaugurate the modern approach to anatomy.

This vision of human being outlined above, received its clearest expression in biomedicine. The biomedical approach to disease is an expression of a broader scientific rationality that subjugates the immediately felt experience of the body in distress. The biomedical model is essentially a metaphorical framework. Stein (1990) remarks that 'biomedical diagnosis reduces the ill person to a metaphoric image of a presenting symptom or disease' (p.171). The task of medicine becomes one of gaining mastery over the diseased object. The following section addresses some of the metaphors propagated by the medical model and the implications of these metaphors in relation to HIV/AIDS.

1.1.2 Biomedicine and HIV/AIDS

Situated in a legacy of Cartesian dualism, the medical model expresses the dualistic values of Western metaphysics. The first notable polarity is that between body and mind. The medical model is responsible for envisioning the body as a self-contained, physical entity existing in itself apart from the world and it is understood in terms of physical mechanisms. Harms (1984) comments that humans are equated to organisms, part of an objective reality which is absolute-reductionist, materialistic and monistic. The dominant metaphor of biomedicine is 'the body as a biochemical machine' (Osherson & AmaraSingham, 1981, cit. in Kirmayer, 1988, p.57). If the body is a physiological machine, then all of its 'functions can be described in biological terms and rationalized for efficiency' (Kirmayer, 1988, p.59). As a machine the body is a system of medical facts and is amenable to objectification. Sickness is perceived as a product of biological destiny located within the physical body and therefore requires the intervention of technology to correct what is considered faulty.

Kirmayer (1988) suggests that concentrating on the body as machine, 'isolates the emotional significance of illness' (p.60), and demands that patients adopt the detached perspective of the scientist towards their own bodies. Clinicians are extricated from the individual's lived experience of illness, operating at a level of abstraction, whilst people tend to live their illness in conformity with a medical view. Diekema (1989) writes that 'many patients complain about

physicians who work as mechanics or technicians, ignoring the full human interaction that promotes patients' involvement with their healing' (p.20). The doctor as technician, parent and fighter are some central metaphors which describe the physicians role in contemporary Western medicine (Stein, 1990).

Apart from perpetuating an ontological dualism between body and mind, biomedicine perpetuates an epistemological dualism between two different ways of knowing. This is manifest in the distinction between disease and illness. Disease is essentially a technical term, an abstract and descriptive conceptualisation of biological disorder. According to Kirmayer (1988), 'disease stands for the biological disorder, or more accurately, the physician's biomedical interpretation of disorder' (p. 59). Illness on the other hand, represents the patient's personal experience. Illness is the subjective response of the patient; it is not only his/her experience of illness but also the meaning he/she gives to that experience (Helman, 1990; Kirk, 1996; Kirmayer, 1988, 1992). The distinction between illness and disease is an important one. McCullough (1989) emphasises that individuals *have* diseases, but they *experience* illness. The biomedical perspective however, emphasises biological disease to the exclusion of illness experience (Kirmayer, 1988; Kleinman, 1988).

Biological disease is essentially conceptualised in terms of the 'germ theory' (Lupton, 1994, p.61). Illness is perceived as an invasive foreign agent attacking the body. Sardello (1988) maintains that 'we are told that some singular part of the body is the site of a morbid condition and are given a label for the situation which enforces a view of disease as an objective entity that has invaded the body' (p.15). This understanding of disease has come to be structured through the military metaphor. Sontag (1989) asserts that 'disease is seen as an invasion of alien organisms to which the body responds by its own military operations' (p.9). It is medicine's intent to gain victory over that which threatens to destroy. According to Stein (1990), 'throughout medical training and practice, war is waged against the *clock*, against *disease*, against practitioner's *loss of control*, against *death*, against the *patient*' (p.67). This metaphorical framework 'survives in public health education where disease is regularly described as invading

the society, and efforts to reduce mortality from a given disease are called a fight, a struggle, a war' (Sontag, 1989, p.10).

Baron (cit. in Diekema, 1989, p.20) points out the implications of conceptualising illness in a technological fashion:

Taking disease to be an anatomic or technologic fact, we are led further away from our ability to understand disease in human terms...our understanding of the nature of disease is limited by our model, and entire aspects of the phenomenon of illness remain inaccessible or incomprehensible to us. In a sense, we seem obliged to remove ourselves from the world of our patients in order to categorize their diseases in a technologic manner. We cannot hear them while we are listening.

Because disease is essentially understood in terms of a contemporary scientific definition, the appropriate response towards the HIV/AIDS epidemic is seen as a medical response. Read (1993) asserts that 'the cause of the disease is seen exclusively within a biological framework, the physical causative agent being HIV' (p.30). AIDS (Acquired Immune Deficiency Syndrome) is defined as the disease caused by the Human Immunodeficiency Virus (Lachman, 1991). In the early 1980's HIV - infection was regarded only as AIDS. AIDS was then described as an acute infectious disease, rapidly and invariably fatal, found almost exclusively in homosexuals. During the late 1980's and the present decade, HIV-infection has been found to be asymptomatic for a considerable time. People who are infected with HIV, will for the most part, live for a number of years. Estimates vary, but in the developed world this life expectancy may be in excess of ten years. In Southern Africa the period is probably much shorter: five to eight years has been suggested (Anon, 1997).

According to medical science HIV attacks and damages the body's natural immune system. By killing or impairing cells of the immune system, HIV progressively destroys the body's ability

to fight infections and certain cancers. During the course of HIV- infection there is a gradual decline in the number of CD4 and T-cells. AIDS applies to the most advanced stages of HIV- infection. AIDS is conceptualised as a medical condition accompanied by a variety of symptoms and signs. As Sontag (1989) points out, 'AIDS is not a single illness but a syndrome, consisting of a seemingly open-ended list of contributing or "presenting" illnesses which constitute the disease' (p.28). The very presence of AIDS requires the presence of other illnesses known as opportunistic infections. For example, people with AIDS are particularly prone to developing various cancers including Kaposi Sarcoma and a cancer of the immune system known as lymphomas.

The biomedical model has important implications for the role of the patient and medical practitioner in the context of HIV/AIDS. Practitioners' understanding of HIV/AIDS structures the way in which individuals come to understand their illness. A study conducted by Norton et al. (1990) investigated the language of physicians in the context of HIV/AIDS, and found that how physicians talked about the disease was often discriminating. For instance, HIV/AIDS was interpreted amongst other things as being synonymous with immediate death.

In biomedicine, the metaphorical understanding of the patient as a physical disease has emphasised the importance of the goal of cure. Society's members have come to believe that the medical practitioner alone knows the cause for their illness and that some form of technological intervention is the only solution (Capra, 1982). Most HIV/AIDS research and concern focuses primarily on preventative and diagnostic imperatives. Read (1993) emphasises that 'most research has aimed at elucidating the physical mechanisms of infection and disease causation, thereby placing the emphasis on the biological aspects of prevention and cure' (p.41). Commenting on the limited nature of response initiatives to the HIV/AIDS epidemic, Saayman and Kriel (1992, p.27) remark:

The main research effort is concentrated on finding a physical cure or a physical means of prevention (a vaccine). As long as these remain unavailable, the only

remedy is education programmes promoting safer sex: All of these approaches adhere strictly to the material and mechanistic assumptions of biomedicine.

Biomedicine's preoccupation with prevention and cure is considered an inadequate response to the phenomenon of illness as well as the social implications which those suffering from illness encounter. As Levin (1987a) points out, 'epidemics that affect our embodiment are not just "medical" problems' (p.24). However, we operate in a framework that sees illness as a temporary challenge to the power of medical technology. In the case of HIV/AIDS, biomedicine has not yet secured a solution to the problem. Although biomedicine may perceive itself to be the "apotheosis" of medical magic (Lupton, 1994, p.53), it is rendered helpless in the face of AIDS. The fact that medicine has been viewed as an age old military campaign now nearing the final phase leading to victory, no longer bears significance. There is therefore a call for alternative ways in which to envision and deal with illness beginning with the question of meaning. As Kolbe (1996, p.235) surmises:

At the core of every illness there is meaning. It is for the physician not only to treat the patient's phenomenological manifestation of the illness, but finally to ask the question: 'What is the meaning of this illness to my patient?'

Kleinman (1988) reiterates this view by professing a concern for the importance of each individual's experience of illness. Based on his work with chronically ill patients, Kleinman emphasises that illness rather than disease should become medicine's chief concern. This implies attending to the individual's experience of illness and the meaning he/she attributes to illness.

Thus far it has been discussed that the metaphorical framework of the biomedical model focuses on issues of disease control, prevention and cure. The body as machine, doctor as technician, and disease as war, are common metaphors emerging from such a framework. The main argument put forth by critics of the biomedical model is that these metaphors isolate patients and

practitioners from the emotional significance of illness. A review of socio-cultural understandings of HIV/AIDS will elicit further metaphors which serve to conceptualise and define the meaning of HIV/AIDS.

1.2 Socio-cultural understandings of HIV/AIDS

In 1977 Dr. Grethe Rask, a Danish surgeon in Zaire, became the first Westerner documented to have died of AIDS. At the time, nobody knew how to talk about the disease. She was reported to have died for 'no apparent reason' (Shilts, 1987). When the first cases of AIDS were reported, doctors, scientists, immunologists, virologists, social scientists, epidemiologists and other professionals did not know how to conceptualise the disease. Until July 1982 it was called 'gay cancer', 'gay pneumonia', or a 'mysterious disease' (Shilts, 1987). In the 1980's AIDS was perceived to be of African or Haitian origin. Haitian migrant workers frequenting central Africa in the 1960's and 1970's were thought to have spread the disease. Alternatively, it has been attributed to deviant USA scientific endeavour. Many doctors, journalists, academics, government officials and other 'educated people' believe the virus was sent to Africa from the USA as an act of bacteriological warfare (Gilman, 1988; Sontag, 1989).

Because HIV/AIDS has been surrounded by ambiguous connotations regarding its origin, it continues to be susceptible to myth and superstition. Today, HIV/AIDS presents itself as a highly metaphorised disease. HIV/AIDS abounds with concocted fantasies, it is shrouded with ambiguous connotation, and stigmatic and pejorative metaphors, exhibiting the ambivalence, fear and uncertainty manifest in society today. Helman (1990) remarks that 'like the plague, cancer and tuberculosis before it, AIDS in the popular perception has become a metaphor - or rather, a cluster of metaphors - and a vehicle for expressing many of the fears and anxieties of modern life' (p.100). The language and the imagery used to describe HIV/AIDS is a powerful determinant of how society perceives those suffering from HIV/AIDS. So too is it a powerful determinant of how AIDS sufferers and HIV-infected individuals experience their illness (Brandt, 1988; Goldin, 1994; Stein, 1990).

Metaphors of ill-health carry with them a variety of symbolic associations which can seriously affect the manner in which individuals perceive their own condition and the manner in which they choose to respond to their illness. According to Stein (1990), both individual and cultural metaphors influence how we feel about our bodies and about ourselves, what we believe our bodies and lives to be and mean, and the kinds of relationships and actions that take place in our world. The following metaphors are common and typical examples of how HIV/AIDS has come to be perceived of, on both a socio-cultural and individual level.

In the early stages of the AIDS epidemic, the death toll was high. Ignorance about the risk involved for each individual, and medical science's inability to successfully treat the disease, enhanced the public's fear of the disease (Read, 1993). This fear and ignorance was largely exacerbated by irresponsible media coverage both written and spoken, on radio and television (Lachman, 1991). Media sensationalism inspired the general population to perceive HIV/AIDS in discriminatory and stigmatising terms.

Erving Goffman (cit. in Brandt, 1985 and Goldin, 1994) presents a typology of stigma that works effectively in the context of Sexually Transmitted Diseases (STD's), in particular HIV/AIDS. The first type of stigma that Goffman speaks of is 'abominations of the body', whereby disease is associated with various images of physical deformity. Sontag (1989) comments that 'the most terrifying diseases are those perceived not just as lethal but as dehumanizing' (p.38). AIDS is associated with a plethora of disfiguring symptoms or opportunistic infections including a skin cancer known as Kaposi Sarcoma. The dehumanising nature of AIDS induces feelings of fear and shame and is expressed in a number of metaphors.

Sontag writes that 'plague is the principal metaphor by which the AIDS epidemic is understood' (1989, p.44). Plague implies the highest standard of collective calamity, evil, and scourge, as well as being a general name for many frightening diseases. For instance, diseases such as leprosy and syphilis have been referred to as plagues. These illnesses are particularly susceptible to being labelled as plagues for they are not only fatal, but transform the body into something

alien and repulsive. These epidemics are further understood to be 'inflicted rather than endured' (Sontag, 1989, p.45) hence the connotation of punishment and judgement. Associating HIV/AIDS with physical disfigurement and judgement includes understanding the disease as a death sentence. This metaphor construes HIV- infection as 'a new, frightening and lurking cause of premature death' (Goldin, 1994, p.1351). The implications of perceiving HIV/AIDS as a death sentence are articulated by Norton et. al. (1990): 'intentionality is involved, somebody gives the death sentence. That "somebody" could be God, a partner, Nature, or the personified virus' (p.820). It also implies that a crime has been committed that deserves a death sentence.

Media coverage on AIDS often dramatises and distorts the physical implications of the disease (Zazayokwe, undated). News media routinely publish or broadcast images of the disempowered, diseased body. Lupton (1994) remarks that people with AIDS are portrayed as ravaged and disfigured, epitomised by the gay man dying with AIDS and marked by the lesions of Kaposi's Sarcoma. Based on sensational media pictorial coverage and the tendency to regard HIV and AIDS as meaning the same thing, feelings of confusion, fear and uncertainty (D'Anzi, 1987; Jackson, 1988) are prominent responses to HIV- infection. Individuals diagnosed with HIV are confronted with fear and uncertainty regarding exactly what it means to be HIV- infected. Often HIV and AIDS are construed as one and the same disease both leading to a swift and agonising death. Yet as Sontag (1989) points out, HIV positivity is not a disease and does not lead immediately to AIDS. Fear of disease, disablement, disfigurement, death, the unknown, blame, stigmatization, social isolation and rejection may also be experienced (D'Anzi, 1987; Jackson, 1988). Confusion and uncertainty are often exacerbated in black communities where people do not understand the concept of disease in terms of Western medicine (Zazayokwe, undated). This sense of confusion has implications for the way in which individuals proceed to experience their illness. For example, HIV/AIDS may be attributed to mythical or supernatural causes or simply ignored.

Another stigma Goffman refers to is 'blemishes of individual character' whereby disease carries with it evidence of moral weakness and transgression. For example, a disease such as

HIV/AIDS is believed to be found among homosexuals and promiscuous individuals. It is commonly viewed as a disease that occurs among those who violate the moral order and is thus considered a fateful link between social deviance and the morally correct (Brandt, 1988). Today, the sexual transmission of HIV/AIDS is judged most harshly. It is an infectious disease in which sexual fluids are considered the bearers of contamination. In effect, this principal means of transmission is considered to put those who are sexually more active at greater risk and as Sontag (1989) claims, 'it is easy to view it as a punishment for that activity' (p.26). Regarding illness as a punishment was prominent in the seventeenth century (Hawkins, 1984) and is one of the oldest idea of what causes illness (Sontag, 1989). Lupton (1994) writes that 'illness was commonly spiritualised by the Puritans as a corrective or punishment of God the Father, and often seen in providential terms, in which guilt and a sense of sin were prominent' (p.57). Most metaphors concerning HIV/AIDS as a judgement and a punishment, link the disease to an angry God. It is referred to as; 'the wrath of God', 'God's judgement', 'sin', 'punishment for sin' - also 'innocent sufferer' (Norton et. al., 1990, p.821).

The third type of stigma is a 'tribal stigma of race, nation and religion'. A disease such as HIV/AIDS is seen as an affliction transmitted through race and nation, equally contaminating all members of the group. In the case of HIV/AIDS, the afflicted group is depicted as the HIV/AIDS 'risk group'. A notion of 'risk group' has negative connotations in that it allows the rest of society to simultaneously assign blame, and through contrast, define their own innocence. A polarity of innocence/guilt is set up 'which allows individuals to dissociate themselves from the disease by disavowing membership in identified risk groups' (Goldin, 1994, p.1360). Kleinman (1988) writes that 'the stigmatized person is defined as an alien other, upon whose persona are projected the attributes the group regards as opposite to the ones it values' (p.159). Feelings of guilt and anger (D'Anzi, 1987; Jackson, 1988) are commonly experienced by HIV- infected individuals. People may feel acute guilt at having contracted a sexually transmitted virus (Jackson, 1988) whilst anger is often directed at oneself, others or God for allowing this illness, with its certain death and shame to happen (D'Anzi, 1987).

In relation to HIV- infected people, society may harbour feelings of blame, hostility and anger. These feelings are bound up with fears of contagion, fear of the unknown, fear of death and dying, and discomfort with sex, sexuality and sexual behaviour (Dunkel & Hatfield, 1986; Zazayokwe, undated). Gilmore & Somerville (1994) point out that ‘stigmatization, scapegoating and discrimination in relation to people living with HIV- infection and AIDS enables us to distance ourselves from our deepest fears, in particular the fear of death’ (p.1353).

1.2.2 Illness and Metaphor - Sontag and her Critics

The metaphors implicit in socio-cultural understandings of HIV/AIDS have immense implications for all individuals, directly and indirectly affected by illness. It is therefore not surprising that the study of metaphor in illness has become a controversial topic of inquiry. Studies of illness and metaphor remain a fairly recent phenomenon starting with Sontag (1979). Sontag’s popular and provocative polemic *Illness and Metaphor* (1979) and later *AIDS and its Metaphors* (1989) served to lay the foundations for critical inquiry into the field of metaphor and illness. A variety of writers such as Brandt (1988), Gilmore & Somerville (1994), Goldin (1994), Norton et al. (1990) and Ray (1989) have studied the meanings of social, moral and stigmatic metaphors surrounding the disease of AIDS. Examining the studies that have addressed the nature of metaphor in chronic illness, Stibbe (1996) succinctly summarises the ideas that have been expressed.

Stibbe concludes that most studies on metaphor and illness focus on the destructive impact of negative metaphors. Some studies acknowledge that metaphors are essential to our thought processes. The majority of studies do not acknowledge that metaphors can be positive and helpful, that metaphors which are removed require replacement, and that the effect of metaphors depends on the situation and individual concerned (Stibbe, 1996, p.156). According to Stibbe, Sontag has exerted a powerful influence on the studies that have taken place regarding metaphor and illness. Stibbe recognises that this may be due to Sontag’s desire to “de-mythicise” negative metaphors.

In assuming a stance oriented towards the eradication of metaphor, Sontag advocated that the healthiest way to perceive illness was one 'purified of and most resistant to metaphorical thinking' (1979, p.3). Metaphors were interpreted as 'lurid', 'punitive' or 'sentimental fantasies'. As Sontag (p.14) states:

The purpose of my book was to calm the imagination not to incite it... not to confer meaning...but to deprive something of meaning: to apply that quixotic, highly polemical strategy "against interpretation," to the real world this time. To the body.

Sontag's main criticism with regards the metaphors surrounding HIV/AIDS is that HIV/AIDS seems to 'foster ominous fantasies about a disease that is a marker of both individual and social vulnerabilities' (p.65). She shows how HIV/AIDS has been interpreted through a variety of metaphors, the majority of which are pejorative. Sontag (1989) writes that 'AIDS has a dual metaphoric genealogy. As a micro-process, it is described as cancer is: an invasion. When the focus is transmission of the disease, an older metaphor, reminiscent of syphilis, is invoked: pollution' (p.17). According to Sontag, metaphorical construction damages the patient's perception of him/herself, the clinicians' perception of the patient, and society's perception and behaviour toward people diagnosed with symbolically burdened afflictions.

It is with the recent call for a paradigmatic shift towards the extrapolation of meaning in illness, that Sontag's desire to deprive illness of meaning has been criticised. Sontag's solution to the excess of meaning and metaphor in illness has been considered an attempt to 'retreat into the radical materialism of biomedicine' (DiGiacomo, 1992, p.117). For instance, in speaking of cancer, Sontag argues that liberation will come when cancer is seen as *only* a disease. Yet, and as Scheper-Hughes & Lock (1987) argue, one has to ask the question; who actually experiences illness in strict physiological terms? No-one ever experiences cancer as the uncontrolled proliferation of abnormal cells.

Levin (1987a) views Sontag's attempt to eviscerate meaning from all disease as embodying a particular stance. He refers to Sontag's position as 'a symptom of and an unwitting contribution to the growing nihilism in our epoch. It reduces illness to just one more totally meaningless event' (p.71). Levin (1987b, p.165) comments:

...it reinstates the hegemony of the orthodox Cartesian paradigm of embodiment. Disease in the dualistic orthodoxy is presumed to inhabit a purely material, machinelike body distinctly separate from the mind. Disease is knowable as the simply physical, through reductive analyses unencumbered by the complexity of subjective meanings.

Brandt (1988) is another who has criticised Sontag. His argument is that disease cannot be freed of metaphors because the process by which disease acquires meaning and value is ubiquitous. Disease is simply too significant, too basic an aspect of human existence to presume we could respond in fully rational or neutral ways. Brandt proposes that 'rather than decrying the metaphorization of disease, it seems more appropriate to analyse the process by which disease is given meaning' (p.418).

The task of forging a psychological understanding and response to the enormity of the HIV/AIDS pandemic may be perceived as an urgent and arguably necessary challenge facing all cultures today. According to Brandt (1988), it is 'only when we recognise the ways in which social and cultural values shape the disease' that we 'will we be able to begin to deal justly, humanely and effectively with a problem as serious and complex as AIDS' (p.432). If a disease such as HIV/AIDS is to be released from its captive imaginings, it is evident that what is needed is an understanding of how the individual experiences and embodies the meaning of illness authentically.

As Levin (1987b, p.165-166) asserts:

Idiomatic metaphors about [AIDS]... attempt to formulate a relevant discourse about what [AIDS] means for us in terms of both the social/productive organization of modern culture and the texture of our personal lives situated in that concrete historical context. The capture of that idiom by the apparatus of social control must be deconstructed. The most thoroughgoing deconstruction of the captive imaginings about [AIDS] will necessarily depend upon an understanding of how the embodied individual experiences illness meanings authentically. This is no less a project than the penetration of the opaque objectivity of the simply material body of disease, the overthrow of the positivistic paradigm of embodiment that forms the principal ideologic superstructure of technologic culture.

Sontag's argument for the abolition of metaphor is valid in so far as socially and culturally defined understandings of HIV/AIDS can exert a negative impact upon individual experiences of illness. The psychological and emotional responses to HIV- infection are immense (D'Anzi, 1987). Apart from some of the individual responses to HIV- infection already mentioned, individuals may experience feelings of reduced support, anxiety, depression, isolation, alienation and expendability (D'Anzi, 1987). Many of the metaphors surrounding HIV/AIDS contribute towards these feelings and it is for this reason that Sontag's argument emits such influence. However, many would agree (Brandt, 1988; Levin, 1987a; Levin, 1987b; Scheper-Hughes & Lock, 1987; Stibbe, 1996) that counteracting the ignorance, fear and stigma surrounding HIV/AIDS does not lie in decrying the metaphorisation of disease and reducing illness to a meaningless event. What should be explored is how these metaphors directly affect those experiencing HIV/AIDS.

1.3 Towards a Revisioning of the human body and illness

Critics of both the biomedical model and Sontag's position regarding metaphor in illness have acknowledged the need for a paradigmatic shift towards a reinvestment in meaning. A

reinvestment in meaning implies a revisioning of the way medicine has come to conceptualise and speak about disease (Bjork, 1983; Diekema, 1989; McCullough, 1989; Norton et al., 1990), in order to accommodate each individual's unique experience of illness. Biomedicine cannot continue to exist in its capacity of separating human experience of illness from what medicine conceptualises as disease. In order to shift the emphasis from the *knowledge of disease* to the *experience of illness*, there is firstly a call for a return to the lifeworld of the individual experiencing illness and a move towards exploring the metaphoric constructions of illness experience (Czechmeister, 1994; Grothmarnat, 1992). It is acknowledged that physicians often take the metaphoric constructions of illness experience for literal statements within the empirical realm of biomedicine. Kirmayer (1992) points out that 'the inability to see the metaphoric and contextual basis of discourse limits the physician's comprehension of the patient's life world' (p.339). Secondly, if a reinvestment in meaning implies returning to the lived world of the individual experiencing illness, the body can no longer be envisioned as an object dislocated from the world and separate from the mind. The main proponents of such a view emerge from an existential - phenomenological philosophy.

Although modern medicine may be little concerned with the existential meaning of illness, phenomenologists such as Boss (1979) and Van den Berg (1972a, 1972b) concede the meaning of illness to be vital. Boss perceives the natural-scientific approach to dealing with illness to be entirely incapable of bringing forth an adequate understanding of illness. Its inability to effectively understand illness phenomena is largely due to the fact that it confronts a realm to which it cannot gain access. According to Boss (1979), it is only the fullest possible articulation of this realm from a phenomenological point of view that can ensure an adequate understanding of the human being in health and illness.

The following two sections of the literature review are concerned with establishing a phenomenological approach to illness. As was mentioned in the Chapter One, phenomenology provides an invaluable approach to the phenomenon of illness because it seeks to understand such an experience by participating in the lived world of the individual. Furthermore,

phenomenology affords epistemological and ontological primacy to metaphor (Brooke, 1991). In effect, it provides a valid means for understanding how metaphor is embodied and lived out in illness.

2. RECAPTURING IMAGINATIVE AND IMMEDIATE EXPERIENCE - attending to our metaphorical existence

Through the pain and suffering that foreshadow its own mortality, the body drives us to seek meaning ... (Kirmayer, 1992, p.325)

In section one it was established that the medical model does not provide an adequate framework for accessing authentic meaning in individual experiences of illness. A paradigmatic shift towards the lived world of those experiencing illness is required. This study proposes that one way of accessing the meaning inherent in individual experiences of HIV, is through exploring the metaphors which impact upon the way individuals come to understand, experience and live with their illness. In order to explore the question of this study, an understanding of the potency and ontological import of metaphor is required. As was mentioned in Chapter One, metaphors are not simply ideas, images or imaginative expressions, but lived realities that influence and shape experience.

Romanyshyn (1973, 1975, 1982, 1984) and Hillman's (1977, 1990) revisioning of modern psychological thought and their attempt to recover the way in which world/others/ and body are inherently metaphorical in character, provide a basis from which to understand the ontological significance of metaphor. Hillman and Romanyshyn give expression to the way in which we are situated imaginatively in and toward the world. Hillman's understanding of soul as the imaginative possibilities in our nature, affords insight into the manner in which we purposively act out an existence in imagination. Given their respective attention to the metaphorical grounding of psychological reality, their work invites a response to illness which is fundamentally imaginative rather than one which is literal (scientific).

This section of the literature review also concentrates on establishing a phenomenological understanding of the body. A phenomenological understanding of the body seeks to establish the body as a meaningful subjectivity which is both a constituting power and constituted world. Through an analysis of the psychological body, it is revealed that metaphor has ontological

importance and can be perceived to be an *embodied* perspective.

2.1 Metaphor as authentic grounding of existence

2.1.1 Romanyshyn and metaphorical reality

As was discussed earlier in section one, the fundamental ontology informing our modern culture today is that of an incompatible dualism. It is the separation of human experience from the world in which experience immediately takes place. This dichotomy originated in the sixteenth century and achieved its clearest philosophical expression with Descartes during the seventeenth century. The Cartesian man/woman was imagined as an encapsulated subjectivity interacting with a physiological body which was part of a material world. If Descartes's philosophy resulted in the separation of man from the world, it also served to imagine a world in which there was 'no space for anything intermediate, ambiguous, and metaphorical' (Hillman, 1977, p.1).

Romanyshyn (1982) traces the birth of the scientific attitude, its decisive impact upon modern psychological life, and the way in which it conceals the inherently metaphorical nature of reality. According to Romanyshyn, 'in the natural attitude of daily life we live on an empirical level with things and with our own bodies, we take these realities *matter of factly* and as *matters of fact*' (p.18). Psychological life appears today 'in a world defined by physics and within a body defined by physiology' (p.24). The consequence of this reflection is that psychological life appears as an *interior event*. Furthermore, 'the experience of the world as an event inside the subject, becomes *literalized* inside the physiological body' (Romanyshyn, p.33). What this implies, is that in order to understand psychological experience, one must remove oneself from the world and retreat inside the physiological body. Literalization conceals the original metaphorical character of human psychological life whilst interiorization essentially obscures the unity of human being.

However, and as Romanyshyn (1982) emphasises, 'psychological experience does not occur as concrete, empirical, factual, physiological events (p.33). Rather, 'psychological experience

is visible through the things of the world. Psychological experience is a world' (Romanyshyn, 1982, p.38). To understand human psychological experience is not to retreat inward - away from the world - but to perceive how human experience is reflected through the world. Romanyshyn's thought is essentially grounded in a phenomenological philosophy. A phenomenological stance is antithetical to a scientific stance in that it embraces and remains faithful to experience as it is imaginatively and immediately lived. A scientific philosophy forgets things in their immediate and original givenness and remains distrustful of experienced appearance. Phenomenology on the other hand, is attentive to that which immediately presents itself and this will be made clear throughout the course of this thesis. Phenomenology also seeks to undercut the subject-object dualism inherent in scientific thought, by extrapolating how human existence is constantly in dialogue with a meaningful world

Drawing from a phenomenological philosophy, Romanyshyn claims that there is a fundamental and primary way of seeing and experiencing things that is neither empirical nor factual - but imaginative and metaphorical. If we are faithful to psychological experience as it is immediately and imaginatively experienced, then we are led 'beyond fact and idea, thing and thought, empirical and mental reality toward a metaphorical reality' (Romanyshyn, 1982, p.148). Romanyshyn (1982) emphasises that if we are to understand psychological life, we must 'recover the place which the imaginal - the image, the reflection - has in our lives' (p.89). Through *imagining*, the way in which things appear is deepened. Romanyshyn is steering us towards an appreciation of the way metaphor affords a deepening of reality. He asserts that 'an imaginal understanding of others and ourselves is the texture of human life' (p.89).

When applied to the context of this research, Romanyshyn's understanding of psychological experience provides a response to illness which is essentially imaginative. There is a distinction between understanding experience meaningfully (imaginatively) and understanding experience literally. Rather than reduce the experience of illness to empirical, physiological facts as biomedicine would do, and gather a factual account of what it means to live with HIV, individuals should be asked how they imaginatively experience such an illness. This would

entail exploring the images and metaphors that make up each individual's experience of illness. Romanyshyn's assertion, that psychological experience is a world, also implies that the fantasies mediating individuals' experience of illness cannot be explored by retreating inward. If human experience is reflected through the world, then it is by inquiring into each participant's world, that an adequate understanding of illness may emerge.

2.1.2 Hillman's ideas on imagination and illness

Hillman's (1977, 1990) ideas on imagination, soul and illness, provide a starting point from which to explore the experience of HIV in a meaningful way. Hillman introduces a new way of envisioning illness by focusing on the fantasies of illness as spoken through soul. He concedes the meaning of illness experience to be given through the voice of soul - which is imagination.

Hillman, in his endeavour to put forward a 'poetic basis of mind', makes the imaginal world the matrix of all his theorizing. In his desire to 'save the phenomena of the imaginal psyche' (1977, p.3), Hillman's poetic vision calls for a psychology that takes its starting point in the processes of the imagination. He asserts that, 'imagination is the only reality, directly presented, immediately felt' (1990, p.86). According to Hillman, imagination is the definitive characteristic of soul/psyche. Everything we know and feel is made up of psychic images. He describes man as 'primarily an image maker and our psychic substance consists of images; our being is imaginal being, an existence in imagination' (1977, p.23).

If imagination and fantasy supercede all reality, then the world in which we live must be seen as primarily imaginative in nature. Hillman (1977, p.23) asserts:

Since we can know only fantasy-images directly and immediately, and from these images create our worlds and call them realities, we live in a world that is neither "inner" nor "outer." Rather, the psychic world is an imaginal world, just as image is psyche.

Hillman is implying that psychological life is structured metaphorically. Psychological reality

essentially represents a third reality between object and subject, mind and matter, as opposed to reality that is grounded materially or located exclusively in the mind. This third reality is known as 'essa in anima' - reality of the soul. Hillman (1977) describes this as a place of soul, a world of imagination, passion, fantasy, reflection that is neither physical and material, nor spiritual and abstract yet bound to them both. Metaphor is considered the authentic grounding of existence, all reality being ultimately mediated through the imaginal dimension of the psyche.

Hillman regards imagination as the primary activity of soul and fantasy images are considered the privileged mode of access to the soul. Hillman uses the term psyche and soul interchangeably. When Hillman (1977) speaks of soul, he means, 'a perspective rather than a substance, a viewpoint towards things rather than a thing itself' (p.x). Soul moves one towards the depth and intensity of experience. Soul is considered 'the imaginative possibility in our natures ... that mode which recognizes all realities as primarily symbolic or metaphorical' (p.x). Hillman's concept of psyche/soul as an *imaginative perspective*, is an attempt to radically revision the way in which modern psychology has come to conceptualise and regard human behaviour. He criticises the literal stance of modern science and calls for an imaginative perspective with which to explore phenomena. Acknowledging that the imaginal depth of things is their reality, results in a vision which is not only thoroughly psychological, but also leads one into the realm of soul. To see through the literal to the image is to reveal the depth of experience and glimpse soul. Imagistic perception is synonymous with psychological vision. Hence, to perceive a person's essence, Hillman proposes that we look into his/her imagination and see what fantasy is creating his/her reality.

With regard to the phenomenon of illness, Hillman strives to give validity to the 'soul's sickness imagery and sickness experience' (1977, p.58). He criticises the medical approach to illness because it does not invite a meaningful or soulful response to the phenomenon. Hillman asserts that 'although falling sick may belong to medicine, the fantasy of it belongs to soul' (p.78). Hillman (1977) writes that 'because the reality of the fantasy comes before the reality of the illness, illness too requires looking at with a psychological eye' (p.80). Even parasite-

caused diseases, or those brought on through accidents, epidemics, or degenerative processes, seemingly organic and so external and “unpsychological”, all have their significance in the language of fantasy. The illness becomes symbolic of something beyond itself, a punishment, a judgement, a personified figure of a demon. Metaphor in this instance is considered the authentic language of the psyche.

If image and fantasy are the language of the soul, accessing the depth of what it means to experience illness entails looking into the imaginations of those who suffer from illness. In view of Hillman’s perspective, understanding the experience of HIV in a meaningful way, entails inquiring into the imaginations of HIV- infected individuals and exploring the fantasies that make up their illness. Working from this stance, it is easy to see how Sontag’s desire to deprive illness of meaning reveals a typically positivistic mode of thinking. It refuses to acknowledge our fundamental grounding in imagination. It is not difficult to see what Hillman’s argument would be in this case. Psyche/soul is essentially grounded in imagination, and the ‘fantasies of sickness are assumed from the outset and in entirety to be part of the psyche’s depth’ (Hillman, 1977, p.84). Hillman suggests that it is important to follow the imagination, follow the soul wherever it leads in order to understand what meaning is being created. The soul needs to be met with imaginal thinking.

Thus far we have seen that both Hillman and Romanyshyn invite what can be termed an imaginative response to illness. Both Hillman and Romanyshyn suggested that reality is inherently psychological, constituted via the imaginative faculties of the existential subject. Accessing meaningful accounts of the experience of illness means adopting imaginal understanding and looking at the fantasies, images and metaphors that make up such an experience. Hillman and Romanyshyn’s understanding of psychological reality also suggests that metaphor is not simply an epistemological device but of ontological importance. Metaphor can be perceived ontologically as a mode of being, or psychologically as a style of consciousness. Hillman (1977) claims that ‘metaphors are more than ways of speaking, they are ways of perceiving, feeling and existing’ (p.156). Thus metaphor is not simply an epistemological device

but lived behaviour, an embodiment of psychological life. A phenomenological analysis of the human body will show how metaphor is an embodied perspective.

2.2 Metaphor as embodied perspective - towards a revisioning of the human body

Kirmayer (1992) claims that 'any theory of meaning that hopes to address the experience of illness must give due weight to the primacy of the body' (p.325). Sickness places the body in the foreground. In illness we are called back to the body, in illness the body demands to be heard. Indeed Kast (1992) writes that 'perhaps illness is motivated by the challenge to once again identify with the body, for the initial purpose of every illness is that we pay more attention to our body' (p.134).

To formulate an adequately psychological understanding of the body, one must begin by abandoning all notions of the body as self-contained, physical entity existing in itself apart from the world. Boss (1979) concedes that 'we can never grasp the phenomenon of bodyhood if we continue to imagine it as a self - contained physical structure existing in itself and of itself, in isolation from the world' (p.102). The aim of this section is to arrive at a phenomenological understanding of the body. This entails envisioning the body as a meaningful subjectivity, as put forth by Merleau-Ponty (1962), which is in dialogue with a meaningful world and is metaphorical (Romanyshyn, 1982) by nature.

Phenomenology seeks to understand the human body as more than the body of physiology. Merleau-Ponty (1962) is perhaps the forerunner in providing a philosophy of the body. Accentuating the corporeality of the existential subject, Merleau-Ponty understands the body as a subject which constitutes meaning and arranges its perceptual field. The body is both a constituting power and constituted world. The central mystery of the body is that it belongs to the visible, that it can be seen, while at the same time it is also a fully embodied world. In other words, the body has a 'dual nature as visible, tangible object and power of vision, receding from

the visible to reveal a world' (Jager, 1984a, p.56). The body is a meaning - giving existence which arranges its world around itself. As Kwant (1968) points out, 'the body is a subject and as a subject is a source of meaning - it is a dialectic interchange with the world' (p.124). Referring to Merleau-Ponty's understanding of the human body as subject, Kwant (1963, p.15) writes:

The body itself precisely as a body, is an existence and therefore of a subjective nature. The body itself is a subject and therefore does not derive its subjective character from a principle distinct from itself.

Many phenomenological writers including Boss (1979), Heidegger (1962), Romanyshyn (1975, 1982) and Van den Berg (1972a), echo Merleau-Ponty's philosophy, in their analysis of the human body as the incarnation of psychological life. They aspire to extricate the human body from the domain of nature where Descartes placed it and reintegrate it into the existential realm. Boss speaks of human bodyhood as the bodying forth of existence whilst Van den Berg elaborates on the body's prereflective and ontological connection to the world of things. Both explore the body in a way that makes sense of what happens to the body in relation to illness. They focus on the changes that take place when the embodied dimension of human existence encounters illness. Romanyshyn seeks to describe the inherently metaphorical character of the body of human behaviour. This corpus of understanding will constitute the literature on the body.

2.2.1 The human body as open presence to the world

Jager (1984a) maintains, that in phenomenological thought, 'the most immediate and primordial experience of the body is precisely that of a certain power of revelation' (Jager, 1984b, p.159). Every aspect of the body accords us a certain access to the world. Jager (1984a) points out that 'it is only as dwelling, embodied beings that we find access to a world' (p.51). The body enters the world as an intentional existence which is open and present to the world. De Waelhens (1967) asserts that one is one's body because one is present to the world. In being present to the

world, the body exists as a particular standpoint. As Parker (1985) attests, 'it is precisely as a body that I have a particular standpoint, or point of view on the world' (p.184). As open presence to the world, the body exists in continuous relationship to the world.

Boss (1979) explores the relationship between body and world in terms of the concept of human bodyhood. Boss's conception of bodyhood is essentially an extension of Heidegger's notion of *Dasein* as embodied. For Heidegger, as becomes clearer in the work of Boss, the body is 'the bodying forth of human existence, and it is only in terms of those existential relations that it can be adequately understood' (Brooke, 1991, p.88).

According to Boss (1979), there is no manifestation of human existence which is not bodily. Boss's conception of bodyhood recognises all bodily phenomena of human existence as the bodying forth of the relationship to the world in which and as which a particular *Dasein* is existing at a given moment. Human bodyhood is *always* the bodying forth of the ways of being in which we are dwelling and which constitute our existence at any given moment. As Boss (1979) writes, 'bodyhood occurs exclusively as the bodying forth of one's existential dwelling amid the beings that address themselves at any given time to his perception' (p.103). It can then be said that the borders of human bodyhood coincide with those of a person's openness to the world. Human bodyhood is such because existence is itself spatial. Body and world are intimately entwined.

If the borders of human bodyhood do indeed coincide with those of a person's openness to the world, it becomes obvious that the borders of the human body extend beyond those of the physical body. Boss (1979) emphasises that there is a fundamental distinction between the limits of our bodyhood and the material borders of inanimate objects. If human bodyhood were a physical material body, then its borders would be the skin. Yet we are always in some sort of relationship to something outside our skin. For example, if one were to look at or imagine a pleasant, scenic view, one immediately body's forth a particular relationship to that view. As an open and expansive presence to the world, one spans and dwells in that perceiving relationship

to the view and is no longer aware of oneself as a self-contained, physical object.

Thus far it has been acknowledged that the human body is a meaningful subjectivity which exists as an open presence to the world. Romanyshyn (1975, 1982) and Van den Berg (1972a) propose that this relationship is metaphorical in nature.

2.2.2 The human body as a metaphorical body

In proposing that the body inhabits a phenomenological space which is itself structured metaphorically, Romanyshyn (1975, 1982) seeks to recover the human body as a psychological body. His aim is to articulate how the matter of the body matters in another way. According to Romanyshyn, the human body cannot be adequately understood as the body of physiology. The human body is discontinuous with and is more than the body of physiology. It is a meaningful subjectivity which figures itself in the world metaphorically. According to Romanyshyn (1975), 'it is only the human body that is capable of creating a metaphor' (p.443). Romanyshyn (1975, p.451) claims:

The human body inhabits a phenomenal world, by which we mean a world inexhaustively rich in its possibilities, always elusive, always an absent presence in relation to which human expression is forever capable of being incomplete, forever capable of being a point of view, and thus forever necessary of being a metaphor of things.

Romanyshyn (1975) asserts that 'we can and in fact do speak metaphorically, because we first live the world in a metaphorical way' (p.452). The subject who speaks metaphorically is and has already been a subject who behaves metaphorically in the world. If, as Romanyshyn claims, the body is capable of creating a metaphor, then this suggests that metaphor has ontological importance. In other words, metaphor may be embodied and lived out. Indeed Romanyshyn suggests that metaphors are embodied, lived realities that profoundly influence and shape experience.

When one speaks of metaphor one usually classifies or refers to it as a '*figure of speech*'. Romanyshyn emphasises the importance of grasping what "*figure*" in fact implies or represents. The body represents the *figure* implicit in the linguistic conceptualisation of metaphor. The body is the concrete enactment of, and gives expression to metaphor. Acknowledging the ontological import of metaphor is to see that metaphor is in fact a figured or embodied perspective. It is interesting to note that the literary critic Kenneth Burke (1945) writes that 'for metaphor we could substitute perspective' (p.503). Romanyshyn emphasises that each perspective is embodied, figured in a concrete way.

In order to emphasise how metaphor is a figured perspective, Romanyshyn (1982, p.163) uses an example from Ortega y Gasset in which he compares what the earth means for a peasant and an astronomer. For the peasant "it is enough to *tread* the planet's reddish brown skin and *scratch* it with his plow; his earth is a *path*, some *furrows* and a *field of grain*." On the other hand, "the astronomer must *determine exactly the place* which the globe occupies at every instant within the *enormous supposition of sidereal space*; the *point of view of exactitude* obliges him to convert it into a *mathematical abstraction*..." For each one the earth opens in a different way. The peasant knows the earth through his crops and in his hands. The astronomer knows it through his numbers and in his mind. Thus, Ortega writes that "Each 'thing' is ... *many things*" [and that] it has no being 'in itself' but gradually acquires one in the different vital *functions* which it assumes."

Romanyshyn proceeds to explain that these "functions" are the enactment of one's perspective, the figuring of it, its embodiment. They are 'the *treading* and this *scratching* of the earth, the *exact determination of its place*' (p.163). Here we see how metaphor is not simply an epistemological device but has ontological importance. It is an *embodied* perspective.

Van den Berg's (1972a) understanding of the body complements Romanyshyn's notion of metaphor as embodied in a concrete and purposive manner. Van den Berg (1972a, p.57) articulates the ontological unity between the embodied dimension of psychological life and the

world with the following example:

A young girl plans to enjoy an evening out. She puts on her best dress, applies makeup and admires herself in the mirror. When she is ready, “she examines the results in the mirror, or rather, she has other people, seeing through her eyes, look at that girl in the mirror.” She imagines others commenting on her appearance and “gets up for a moment or two, and trips about in her room.” As Van den Berg writes, “*She is in the city already, then*; otherwise she would not walk like that, nor could she look so sexy.” Her behaviour changes upon saying farewell to her parents. She is still situated in her childhood surroundings. Her body gives a corresponding response to what her parental home is shouting at her, “You are a child!” Upon arriving in the city, other words reach her. The way people look at her tells her that she is a mature woman. “Again her body responds: it trips about and looks sexy.”

In other words, Van den Berg is describing the manner in which the psychological body can be perceived as a presence or disclosive openness to the world. In the relation of body and world, neither of the two is second. Van den Berg (1972a) asserts that ‘the body forms itself in accordance with the world in which its task lies’ (p.58):

It takes on a form, a figure: a working figure, a fighting figure, a loving figure. But one is equally justified in saying that the world is changed by the body moving about in it. Objects take on different shapes, working shapes, fighting shapes, loving shapes. Do objects look different to the fighter and to the peaceful person? Objects *are different* to them. Thus, prereflective body and prereflective world are united as in a dialogue.

Like Romanyshyn, Van den Berg implies that the body figures itself in the world metaphorically. Perceiving the body as open presence-to-the-world allows an understanding of the way in which illness comes to be embodied as a *world*. In illness something happens to the body and the way in which one finds oneself situated therein. A disturbance in the

bodily sphere alters the way in which the world appears. Romanyshyn would urge one to adopt imaginal thinking in order to see the story in the experience. For example, what does an individual suffering from illness (HIV) find his/her role in the world is now? A fighting figure, an outcast, a sinner?

2.3 Summary and questions

In this section of the literature review, a basis for understanding the metaphorical nature of reality was provided. Hillman and Romanyshyn assert that all reality is primarily metaphorical and all our perceptions are fundamentally imaginative understandings. As human beings we constitute our reality first and foremost, in an imaginative way. An adequate understanding of psychological experience thus entails exploring the images and fantasies that shape reality. If there is a primary way of seeing and experiencing things that is imaginative and metaphorical, then the following questions are of importance in this study: *How do you imagine HIV? Do you have a picture of the virus? Describe it to me. What images come to mind when you think of the virus?*

A phenomenological analysis of the human body sought to emphasise that the life of the body cannot be explained in terms of physiology. It is in no way comparable to a purely physical organism extricated from mind or meaning. The body is a psychological body, continually creating meaning and continually in dialogue with a meaningful world. Jager (1984a) writes that 'bodily existence floods over into things, appropriates them, infuses them with the breath of life, draws them into the sphere of its projects and concerns' (p.55). Furthermore, the body is inherently metaphorical by nature, a purposive and figured embodiment of metaphor, or to use Hillman's (1977) phrase, 'a magnificent citadel of metaphors' (p.174). Establishing the body as such, creates a basis upon which to explore the meaning of the body in dis-ease. In illness we are called back to the body and are urged to witness what meaning the body is creating through the suffering that foreshadows its own mortality.

3. ACCESSING THE EMBODIED METAPHOR

It is the reality of the modern man or woman who no longer lives in the closed temple of egocentric isolation, but in that wide field of interaction, of communication in an emerging, turbulent world. (Van den Berg, cit. in Romanyszyn, 1982, p.xiii)

If the focus of this research is understanding the way metaphor affects the manner in which individuals constitute their world, then it is necessary to ask: What areas of human being need to be explored in order to access the embodied metaphors? The phenomenological approach to illness allows access to human existence as a realm of world openness. It concentrates on the meaning that is elicited throughout an individual's experience of illness. In phenomenological thought, the essence of meaning in the experience of illness is revealed through observing the changes that take place in man/woman's relationship with his/her world/other/body and time. By asking the individual to describe how each of these appears to him/her we begin to see how illness is lived and embodied as a world. The phenomenological approach seeks to capture the experience of illness as it appears, as it is immediately and imaginatively embodied. Both Boss (1979) and Van den Berg (1972a) posit a systematic and descriptive method for understanding the experience of illness. Although their inquiries have been based on mental disturbance rather than physical illness, the literature they provide presents an important reading guide with which to approach the phenomenon of illness.

3.1 Human existence as embodied openness

Boss (1979) proposes the replacing of the natural-scientific paradigm underlying modern medicine with an ontology based upon Heidegger's ontology of *Dasein*. The natural-scientific approach fails to gain access to the whole reality of day-to-day existence because it insists upon narrowly defining human being. In order to propose an adequate existential foundation for medicine, Boss traces the existentials which are most relevant for accessing meaning in the experience of illness. A phenomenological approach opens up an understanding of all the areas of human *Dasein* to which the natural-scientific orientation does not allow access. *Dasein* is characterised by a number of fundamental traits. According to Boss, the most important of these for medicine are, 'the primordial spatio - temporal character of *Dasein*, its

attunement, its bodyhood, its coexistence or being together in a shared world, its openness, the unfolding of inherent potentialities into existential freedom and the existential trait of mortality' (p.199).

Boss examines how these existential traits are impaired in certain modes of illness. He reiterates that the fundamental traits of human being cannot be taken apart and observed one by one. Rather, 'all are inseparable, equally primary, members of the unified structure that is human being-in-the-world, and whenever the fulfilment of any *one* essential trait is disturbed, every other trait as well is affected to some extent'(p.199). In effect, Boss claims that what is actually impaired in a given illness is the ill person's ability to engage in carrying out these particular potentialities as free behaviour toward what he encounters in his world.

When illness impairs the body, there are two questions that should be asked. Firstly, how is the bodily sphere of *Dasein* disturbed? Secondly, what ways of relating to the world have been disturbed? In other words, a phenomenological account of illness asks the following questions; What existential potential is destroyed? What bodying forth of being-in-the-world is being impaired? A closer look at Heidegger's notion of *Dasein* will provide a means of accessing meaning in the experience of illness.

3.1.1 Heidegger's notion of *Dasein*

Committed to the task of establishing a fundamental ontology, Heidegger focused on the question of *Being*. Heidegger's ontology of *Dasein* exemplifies the fundamental ontological connection between the Being of the world and the being of man and establishes how *Dasein* is situated in the world. Heidegger's analysis of the structural constitution of *Dasein* is deemed important for this research for two reasons:

Firstly, Heidegger's notion of *Dasein* makes ontological sense of Hillman's (1977) definition of psyche as perspective, a point made by Brooke (1991, p.79). Both Heidegger's ontology of *Dasein*, and Hillman's understanding of psyche/soul are concomitant, each focusing on the

question of meaning. Imagination is an essential structure of *Dasein* implicit in Heidegger's work (Brooke, p.87). It is acknowledged as 'a characteristic of *Dasein*'s perceptive world-openness, given within *Dasein*'s primordial understanding of the world. There is no perception that is not also an imaginative understanding' (Brooke, p.89). All access to the world is structured imaginatively. Hillman's understanding of fantasy corresponds with Heidegger's recognition of *Dasein*'s perceptions as essentially imaginative understandings. *Dasein* is not a substantiative entity in itself which then relates to the world but is given through things. *Dasein* is ontically indistinguishable from its appearance as things (Brooke, p.89), or the manner in which the things of the world reveal themselves to us.

Hillman (1977), Romanyshyn (1982) and Van den Berg (1972a) all echo Heidegger's view. For example, Van den Berg (1972a) asserts that to understand man's existence, 'we must listen to the language of objects' (p.40). Romanyshyn (1982) speaks of the necessity of recovering the world as the authentic home of psychological life. Hillman (1977) writes that 'in the beginning is the image; first imagination then perception; first fantasy then reality' (p.23).

Secondly, Heidegger's thought on inauthentic and authentic being provides a basis from which to explore and make sense of the potentially transformative nature of illness experience. It has been acknowledged (Frank, 1993; Yalom, 1980) that the experience of chronic illness often brings with it the opportunity for growth and transformation. In relation to HIV/AIDS, Meuller, Medina, Dunbar & Wolf, (1997) assert that HIV/AIDS sufferers have undergone transformative and positive experiences during their illness. Heidegger provides a powerful framework with which to explore how, in the encounter with death (as chronic illness prescribes), human being may be called back from its lostness in the "they" and confronted with the ultimate concerns of human existence such as isolation and meaninglessness.

3.1.1.1 The existential constitution of the "there"

Heidegger postulated *Dasein* to be the distinguishing characteristic of human existence. He was essentially concerned with the existential constitution of the "there" of Being. Human existence

or *Dasein* is essentially an openness to the world, the “there” of Being. Man is not perceived as an encapsulated subjectivity but rather a being-in-the-world, an embodied openness to what is. Heidegger (1962) points out that ‘in saying “I”, *Dasein* expresses itself as Being-in-the-world’ (p.368). Man or *Dasein* cannot be defined without referring to the world - for - ‘to be at all, to exist, is to be with fellow man and things’ (Kruger, 1988, p.33). Experience, self and world are mutually entwined. In other words, “I” am always in the world of my experience. Zimmerman (1981) points out that ‘the world is the interrelated set of relations which give form and content to my experience’ (p.27). Giorgi (1984) reiterates this view, commenting that ‘in the phenomenological viewpoint, the body, world, others and time are differentiable but they are not lived as separate entities’ (p.25). It is important to see these dimensions of human existence as mutually implicative.

Brooke (1991) writes that ‘the term *Dasein* is Heidegger’s attempt to think that ontological openness in which our particular (ontic) spatial relations are lived’ (p.87). The spatial quality of the human world is ‘in no way comparable to the geometric space in which inanimate, “world-less” objects are present’ (Boss, 1979, p.88). It is rather, open and clear to the extent that phenomena may address us through it with their meanings and contexts of reference. Human existence is itself spatial in the sense that the basic characteristic of its existence is openness and receptivity. It is an open realm of perception. As Boss (p.123) comments:

Existence is essentially an openness to perceiving whatever enters the realm of this openness, shines forth within it, and so comes to be present as a being with its own meaningfulness.

To exist as *Dasein* means to ‘sustain and maintain the clearness of a world-spanning realm of perception, to hold open this realm into which whatever can be may shine forth and be perceived in its meaning and its place’ (Boss, p.131). In other words, ‘Human-being-in-the-world, is a multitude of ways of perceiving and responding’ (p.132). To identify the existential spatiality of *Dasein* is to show that psychic reality is world-related (Brooke, 1991, p.79). Boss (1979) points

out that ‘in the form of perceptive connections with all its encounters, each human existence spans the open spatiality of its own world, sustaining it and maintaining its ec-static freedom’ (p.90).

Heidegger (1962), concerns himself with two fundamental modes of existing in the world. Firstly that which he terms, inauthenticity, ‘a state of forgetfulness of being in which *Dasein* is in its everydayness indistinguishable from the deteriorated (verfallen) *Dasein* of the anonymous “they” - *das-man*’ (Brooke, 1991, p.88). Secondly, authenticity, a state of mindfulness of being in which one’s fallenness is appropriated as one’s own.

3.1.1.2 Inauthentic Being

In the beginning of *Being and Time* Heidegger analyses human existence at the level of everyday life. For the most part, *Dasein* is in its everydayness indistinguishable from the deteriorated (verfallen) *Dasein* of the anonymous “they” (Brooke, 1991, p.88). To exist is to be caught up in the world as interpreted by others. In losing itself to the “they” (das man), *Dasein* relieves itself of the burden of authentically choosing the possibilities and potentialities of its own being, and gives itself over to the already understood and interpreted world of the “they” (Parker, 1985, p.17). As Yalom (1980) describes, ‘in a state of forgetfulness of being, one lives in the world of things and immerses oneself in the everyday diversions of life’ (p.30). Due to its lostness, ‘*Dasein* makes no choices, gets carried along by the nobody, and thus ensnares itself in inauthenticity’ (Heidegger, 1962, p.312). As Heidegger (1962) remarks, ‘a mode of being [inauthentically] amounts to a quite distinctive kind of Being-in-the-world, the kind which is completely fascinated by the “world” and by the *Dasein*-with of Others in the “they”’ (p.220).

There are three constituent modes of *Dasein*’s openness to being inauthentic; curiosity, ambiguity and idle talk. Of the three *idle talk*, or *chatter* is the most significant to this study.

In his[her] everyday living, man[woman] cannot help but be influenced by the world-as-already-interpreted that is reflected in idle talk. (Parker, 1985, p.20). The way *Dasein* comes to see

things is influenced by the already interpreted idle talk of the "they". Heidegger (1962) asserts that 'ultimately things are so because one says so' (p.212). Zimmerman (1981) remarks that 'idle talk is the possibility of understanding everything without previously making the thing one's own' (p.56). *Dasein* is constantly delivered over to this interpretedness, which controls and distributes the possibilities of average understanding and of the state-of-mind belonging to it (Heidegger, 1962, p.211). An example of idle talk is that of mass media advertising and in relation to HIV/AIDS is seen clearly in the circulation of sensational media coverage and advertising.

Through idle talk and the way things have been interpreted, man/woman offers to him/herself the possibility of losing him/herself in the "they" and thus constantly brings upon him/herself the temptation of falling. Heidegger uses the word "fallenness" to characterise a *Dasein* diverted from its authentic selfhood. As Zimmerman (1981) explains, falling is 'the inescapable tendency to conceal the truth about ourselves and the world' (p.43). Fallenness is a kind of tranquillising for it takes away from *Dasein* responsibility and the anxiety that goes with it (Parker, 1985, p.24). *Dasein* for the most part exists inauthentically.

3.1.1.3 Towards a mindfulness of Being

In order for *Dasein* to be itself authentically it is necessary that it should bring itself back to itself from the lostness in the "they" (Parker, 1985, p.26). To be its authentic potentiality-for-Being, it must first find itself, since for the most part it has been lost in the "they". In order to find itself, it must be made transparent to itself in its possible authenticity (Parker, p.27). For Heidegger, the phenomenon called "the voice of conscience" is the call back to its own self, of the authentic self to the inauthentic self. In inauthentic being, *Dasein* is absorbed in the "they", and '*Dasein*'s openness is characterised by a tranquillised, self-assured attitude of feeling familiar with and at home in the world' (Parker, p.34). As *Dasein* becomes increasingly inauthentic (p.34):

anxiety brings it back from its absorption in the 'world'. Everyday familiarity collapses. *Dasein* has been individualized, but individualized as Being-in-the-

world. Being-in enters into the existential 'mode' of the '*not-at-home*'.

(Heidegger, 1962, p.233)

As Parker (1985) points out, 'this "not-at-homeness" is the uncanniness which one feels in anxiety' (p.34). Heidegger uses the term "uncanny" (not at home) to refer to the state in which one loses one's sense of familiarity with the world. It is 'this *Dasein*, which finds itself in the very depths of its uncanniness which is the caller of the call of conscience' (Heidegger, 1962, p.320).

Yalom (1980, p.31) writes:

One doesn't move from a state of forgetfulness of being to a more enlightened, anxious mindfulness of being by simple contemplation. There are certain unalterable irremediable conditions, certain "urgent experiences" that jolt one, that tug one from the first, everyday, state of existence to the state of mindfulness of being.

Yalom (1980) writes that of these urgent experiences, 'death is the nonpareil: *death is the condition that makes it possible for us to live in an authentic fashion*' (p.31). *Dasein*, in its very existence, is always ahead - of - itself in living towards the future (Parker, 1985, p.39). The ultimate horizon and possibility of this existence is inevitably death, of which *Dasein* is aware. Hence, at the centre of *Dasein* is mortality - finitude. For Heidegger, *temporality* means that *Dasein* is a being-towards-death. Heidegger (1962) refers to this Being as 'anticipating or anticipation' (p.306). Death is '*Dasein's ownmost possibility*, Being this possibility discloses to *Dasein* its *ownmost* potentiality-for-Being' (Heidegger, p.307). As Parker (1985) writes, 'in this distinctive possibility of *Dasein's* own self, as in the state-of-mind of anxiety (dread), *Dasein* is "wrenched away from" the "they"' (p.39). Realising that death is uniquely one's own, invites one to appropriate it authentically as one's own. As Heidegger (1962, p.311) comments:

Anticipation reveals to Dasein its lostness in the they-self, and brings it face to face with the possibility of being itself, primarily unsupported by concerned solicitude, but of being itself, rather, in an impassioned freedom towards death - a freedom which has been released from the Illusions of the "they", and which is factual, certain of itself, and anxious.

3.2 Confrontation with death - crisis and challenge

Heidegger proposes that affirming and appropriating death as one's own invites one to dwell in a more authentic fashion. Although death brings the threat of extinction, it too offers the promise of transformation. As Yalom (1980) aptly puts it, 'although the physicality of death destroys man, the idea of death saves him' (p.30). Death may therefore be perceived as both a crisis and a challenge, offering transformative potential.

Writers such as Kubler-Ross (1969,1987) and Yalom (1980) have provided significant commentary on the theme of death. Kubler-Ross explores the salient emotional reactions patients and family experience from the beginning of a diagnosis- up to the death of the patient. These 'stages of dying' include; denial, isolation, anger, bargaining, depression and acceptance. Based on his work with cancer patients, Yalom (1980) explores the way in which individuals, upon confronting terminal illness, encounter and deal with certain fundamental existential concerns. Drawing upon certain conceptual aspects of Heidegger's work, Yalom explores how these ultimate concerns, namely; death, freedom, meaninglessness and isolation, are handled. Both Kubler-Ross and Yalom's work bears significance in this instance because it suggests the importance of being attentive to the emotional and existential dynamics inherent in the experience of illness. In relation to HIV, this implies exploring individuals' feelings relating to death, and themes such as isolation and meaninglessness.

3.2.1 Death as crisis

Today we tend to view death more as a crisis than as an opportunity for finding deeper meaning in our lives, a transformative experience. Death is feared and perceived as a threat and 'an intrusion upon the scientific quest for immortality' (Garfield, 1975, p.148). In our modernistic climate death is concealed as a meaningful presence and dimension of human existence. Welman (1996) remarks that 'the existential import of death is veiled in modern life at least partly because the scientific bent to our thinking confines its meaning to a literal event only, and thus as something outside of the boundaries of human experience' (p.9). The fact that our modern age conceals death as a meaningful possibility invariably makes death somewhat more of an enigmatic and isolated event.

Yalom (1980) writes that 'at the most fundamental level, dying is the most lonely human experience' (p.356). Confrontation with death leads to isolation. Existential isolation refers to an unbridgeable gulf between oneself and any other being. It refers too, 'to an isolation even more fundamental - a separation between the individual and the world' (Yalom, p.355). As was articulated in a previous section, Heidegger uses the term "uncanny" to refer to the state in which one loses one's sense of familiarity with the world. When one is totally involved in the familiarity of the world of appearance and has lost contact with one's existential situation, Heidegger considers one to be in the everyday fallen mode. However, 'anxiety serves as a guide to lead one back, by way of uncanniness to awareness of isolation and nothingness' (Yalom, p.359). In being brought back from absorption in the world one experiences anxiety at confronting the world's loneliness, mercilessness and nothingness. Yalom writes that, 'it is a feeling of not being-at-home-in-the-world; that there is no solid ground; that we are not here or there or anywhere in the world' (p.361).

Yalom (1980, p.356) communicates the loneliness of the human encounter with death by way of the medieval morality play *Everyman*. The Christian moral of the play is that good works within the context of religion provide a buttress against ultimate isolation. Today's secular *Everyman* who cannot or does not embrace religious faith must take the journey alone. This introduces an

interesting point regarding the role of religion or spirituality in the experience of illness.

3.2.2 Death and personal change

Although an encounter with death may lead to anxiety and existential isolation, there is evidence of personal transformation in the experience of illness. Kubler-Ross (1987) speaks of how AIDS sufferers have arrived at a profound stage of accepting their illness and experienced personal growth. Yalom (1980) comments on how terminally ill cancer patients have used their crisis and their danger as an opportunity for change. Among these shifts and inner changes, are reports of an enhanced sense of living in the immediate present, rather than postponing life until retirement or some other point in the future, and a vivid appreciation of the elemental facts of life: the changing seasons, the wind, falling leaves, the last Christmas and so forth.

An encounter with death may lead to a more authentic mode of being. Yalom asserts that ‘the recognition of death contributes a sense of poignancy to life, provides a radical shift of life perspective, and can transport one from a mode of living characterized by tranquillization and petty anxieties to a more authentic mode’ (Yalom, p.40). A recognition of death can inspire a shift to a more authentic mode of embodiment. Yalom claims that many patients described a reassessment of priorities; of becoming more passionate and more human oriented than they had been before. In terms of Heidegger’s understanding of *Dasein* and authentic existence, what is embraced is a mindfulness of Being, that ontological mode in which ‘one remains mindful of being not only mindful of the fragility of being but mindful, too of one’s responsibility for one’s own being’ (Yalom, p.31).

3.3 Summary and questions

Thus far, it has been established that a phenomenological approach to illness allows access to human existence as a realm of world openness. Through an analysis of Heidegger’s ontology of *Dasein*, it was seen that human existence or *Dasein* is essentially an openness to the world, the “there” of Being. Man is not perceived as an encapsulated subjectivity but rather a being-in-the-

world, an embodied openness to what is. This laid the grounds for asking; *What bodying forth of being-in-the-world is impaired in illness? What existential potentialities of Dasein are impaired? How is the body unable to do things it once did?* Heidegger's thought on inauthenticity and authenticity served to capture how *Dasein* in its everyday existence lives inauthentically, lost in the idle chatter of the "they". Yet in the encounter with death as HIV/AIDS prescribes, human being may be called back from its lostness in the "they" and confronted with the ultimate concerns of human existence such as isolation, freedom and meaninglessness. An encounter with HIV may lead one to embody a more authentic mode of existence through opening the possibility of authentically embracing guilt, responsibility and most importantly death. In effect, an overarching question might be; *How does (if at all) an encounter with illness move one towards a mindfulness of Being?*

To conclude with the last section of the literature review, mention must be made of the phenomenologist Van den Berg's approach to illness.

3.4 Illness as an embodied world

In his book *A Different Existence* (1972a), Van den Berg claims that the essence of meaning in the experience of illness is revealed through observing the changes that take place in a person's relationship with his/her world/body and time. By asking the individual to describe how each of these appear to him/her we begin to see how illness is lived and embodied as a world. As was mentioned earlier, Van den Berg's approach to understanding the experience of illness is based on mental disturbance rather than physical illness. However, he does provide a thoroughly phenomenological approach to the phenomenon of illness and his work is considered an important reading guide with which to approach this particular question of concern.

Van den Berg emphasises that a phenomenological inquiry into illness seeks to describe an individual's illness from his/her own unique point of view, no matter how much his/her interpretations of illness seem to differ from that which is considered factually. Van den Berg

(1972a) asserts that ‘every patient suffers, apart from suffering from his disease as such, from the disease as it exists in the opinion of his physician. He suffers from his physician’s point of view’ (p.85). The way in which physicians understand and regard illness influences the way individuals are called to live forth their illness. In order to remain true to an individual’s unique experience of illness, the phenomenologist must put himself in the patient’s existence, in his/her world. It is important to know what *his[her] existence is like*. The reality of the patient must be taken completely seriously without the imposition of theory or assumption. Van den Berg (1972a) asserts that it is the task of the phenomenologist to immerse him/herself in how the illness is present to the patient, believing wholeheartedly in the patient’s reality.

This attitude reiterates the intent of the research. Rather than focusing on disease as conceptualised by biomedicine, the research focuses on the experience of illness. In other words, how HIV is present to the suffering individual. Boss (1979) supports Van den Berg’s point of view. He maintains that ‘the attitude towards illness is an important part of the phenomenology of the suffering’ (p.197). In other words, it is important to establish the way in which an individual regards illness. Questions arise such as; is an illness accepted as a challenge, revolted against, surrendered to, or denied its existence?

Van den Berg (1972a) asserts, that remaining true to psychological experience on its own terms entails observing the changes that take place in the appearance of world/body/others and time.

3.4.1 Changes in the observable world

Van den Berg (1972a, p.39) writes:

If we want to gain insight into another person, his condition, nature, habits or disturbances, we should not inquire first about his introspectively accessible subjective accounts of his observations ... We get an impression of a person’s character, of his subjectivity, of his nature and his condition when we ask him to

describe the objects which he calls his own; in other words, when we inquire about his world.

Van den Berg (1972a) maintains that if the world is human nature's dwelling place, then it is the dwelling place also of illness. Van den Berg (1972a) emphasises that 'the relationship between man and his world is so close that it is erroneous to separate them ...' (p.39). He asserts that 'our world is not a conglomeration of objects that can be described scientifically' but rather, 'the realization of our subjectivity' (p.40). To describe another one must 'make an analysis of the "landscape" within which he demonstrates, explains and reveals himself' (Van den Berg, 1955, cit. in Romanyshyn, 1984, p.102). To be ill means that first and foremost one's surroundings have changed. As Van den Berg (1972a, p.45) writes:

To be ill, even with just a trivial illness, as much as with a mortal illness, means, above all, to experience things in a different way, to be different yonder, to live in another, maybe hardly different, maybe completely different world.

To illustrate his point, Van den Berg (1972b, p.26) provides the following example: "If I am sick," he writes, "the world changes ... the world has shrunk to the bedroom, or rather my bed." Van den Berg is speaking metaphorically and is speaking a reality which is in principle metaphorical. How much more do we sense the suffering and isolation when he/she speaks of illness in this way - metaphorically. In light of Van den Berg's observations, it is pertinent to ask how individuals perceive their world in illness, and what kind of relationship they body forth to their world. In other words: *what is HIV like for you and how does it feel? How does the world appear to you on days when you feel particularly sick?*

3.4.2 Changes in the body

In section two it was established that the body is an open presence the world. If the body is open to the world it must also be able to close itself to the world. Kwant (1963) claims that one's body is one's entry to the world, and all the ways in which the world is accessible to a person are

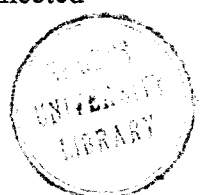
connected with the body. It is precisely the disturbances in the normal conditions which disclose the function of the body. In normal conditions we use the body without acknowledging its importance. Van den Berg (1972b) writes that 'the body is a healthy person's faithful ally ... The healthy person is allowed to *be* his body and he makes use of this right eagerly: he *is* his body' (p.66). When human beings are existing in the most highly characteristic way, they are completely unaware of their body. The healthy person is so much his/her body that he/she actually forgets about it. Illness however disturbs this assimilation. A person's body becomes foreign to himself/herself. An intruder makes it his headquarters and it becomes uninhabitable to the sick person.

In other words, the body one *has* is unlike the body one *is*. Van den Berg asserts that 'a disturbance, a disease, has to enter the body one *is* to make the body one *has* come into existence' (Van den Berg, 1972a, p.50). In physical disease we are called back to the body and may witness the body attempting to make meaning in its illness. It is important to inquire how individuals relate to and inhabit their bodies in illness. In other words: *how do you feel about your body? What has changed?*

3.4.3 Changes in ways of relating to people

Van den Berg (1972a) asserts that 'inter-human relations manifest themselves as physiognomies of a world, as nearness or distance of duties or plans, *of objects*' (p.68). In other words, 'the relationship between man and fellow man is such that it realizes itself in the form, and in the nearness and distance, of world and body' (p.71). Van den Berg points out that 'another person plays a part in one's relationship to one's body. He can make the relationship closer. He can enlarge the distance' (p.69). Love removes the distance between bodies.

If friendship is entering into another's world and being there, seeing the world through their eyes, it is pertinent to ask: what happens when people experience illness? Their world may no longer be that which their fellow man can share. What do they see and what happens to their relationship with body and world? As this review has articulated, body and world are inextricably connected



with one another. Van den Berg (1972a) writes that people can act as an obstacle to the ownership of the body, as an obstacle to ownership of the world. In this instance it is pertinent to ask what an individual's relationship with others is like and how this influences the way in which they inhabit their body and world. In other words: *How did/do people respond to you and you to them? What has changed?*

3.4.4 Changes in past and view of future

As human beings we are always in some sort of relationship with time. An analysis of *Dasein* showed that we exist as a temporal openness. Terminal illness brings with it the reality of death and implies that there may be a disturbance in individuals' relationship to time. A consideration of how individuals perceive their past, live their present, and envision their future affords insight into the meaning they derive in the experience of illness.

3.5 Concluding comments

Given the limitations of the natural-scientific approach to illness, the approach to this research is essentially defined as follows: A meaningful way of understanding the experience of HIV entails inquiring into the metaphors that mediate such an experience. An exploration into the metaphors that mediate meaning in the experience of illness, entails returning to the lived world of the individual experiencing illness and revisioning the body from scientific object to meaningful subjectivity. Certain conceptual aspects of phenomenological psychology have been reviewed in order to provide a basis from which to understand the experience of illness. Phenomenology is essentially an attitude, a way of approaching phenomena in an open and receptive manner. In the literature review this *attitude* and this *approach* have determined certain questions which will guide the methodological procedure of the research. The method used in this study is discussed in the following chapter.

CHAPTER THREE

METHODOLOGY

... everyone lives an existence that is structured, incarnate, interpersonal and historical. This is how it is and not otherwise. (Van den Berg, 1972a, p.104)

The aim of this thesis is to understand what it means to live with HIV by exploring the metaphors which mediate such an experience. As was mentioned in Chapter One, what is considered important in this study is the way in which metaphorical thinking about illness impacts upon individuals' understanding and experience of HIV. In order to arrive at an understanding of how metaphor is embodied and lived out in illness, a method was needed that remained faithful to experience as it immediately appeared and was imaginatively embodied. Phenomenology presented itself as that method.

In order to establish a thoroughly phenomenological approach to this research, the structure and intent of both the conceptual and methodological frameworks of the study will be addressed in this chapter.

3.1 Towards a phenomenological method

3.1.1 Conceptual framework

Although a theoretical framework was needed to elucidate emergent meaning, it is important to understand the capacity within which such a theoretical structure worked. In this thesis, the literature review was itself a methodological process in that it served to render explicit the approach that underpinned and guided the method and content of the research. Romanyszyn (1982, p.136) suggests that:

If we want to remain faithful to experience as it is given, if we wish to remain close to the reality of things as they appear, then we must suspend ... bracket the factual status of things, not because the world and its things are in doubt but in

order to regain the way things come into being.

The decision to put the factual status of things temporarily out of play amounts to the practice of phenomenology. Husserl (1962) describes this as the transcendental attitude, 'a process of phenomenological reduction, suspending or bracketing personal preconceptions and presuppositions by making them explicit' (Stones, 1979, p.142). According to Kvale (1983), the phenomenological reduction does not involve an absence of presuppositions, but a consciousness of one's own presuppositions. What follows describes the approach underlying this research:

The literature review was mainly concerned with establishing a means of approaching the phenomenon of HIV in a meaningful way. A scientific approach to understanding illness was deemed inadequate for revealing the depth of meaning in such an experience. This is primarily due to its commitment to explanation and control. Establishing a psychologically relevant response to illness was founded upon the way in which individuals imaginatively and subjectively experience their illness. In other words, it was decided that the depth of the experience of HIV could be accessed by exploring the metaphors which individuals used to understand and deal with HIV.

In effect, an ontology based on phenomenological psychology and an epistemology based on the validity of metaphor was presented in the literature review. This served to invite an imaginative and meaningful response to illness. Certain questions were also posed in the literature review in order to proceed with the interviewing phase of the research. Although the literature review established questions with which to proceed with the methodological procedure, data collection and explication took place before the literature review was fully integrated and developed as a whole. This emphasised a phenomenological dedication to each participant's immediate and imaginative account of his/her experience.

In the literature review it was suggested that phenomenology was an adequate framework for exploring the question of meaning in the experience of illness. Critics of the biomedical

approach to illness were unanimous in their advocacy of a return to the lifeworld of individuals experiencing illness. Concomitant with this 'call for meaning' was an appeal for a new method with which to approach the question of meaning in illness, explicitly articulated by some as phenomenology. Wikan (1991, cit. in Digiacomio, 1992) hints that if our aim is to understand things that matter rather than things that simply make sense, if we wish to grasp the compelling significance of others' worlds, we must redesign our ways of observing and conceptualising. Kestenbaum (1982) suggests that it is ethically imperative that [health care workers] cultivate a *phenomenological* habit of mind, a new effort of attention, in attempting to understand their patients' experience of illness.

In South Africa, there has been no systematic phenomenological research carried out in the area of HIV/AIDS. Completed HIV/AIDS research in South Africa (reviewed on NEXUS database) has focused primarily on issues such as educative intervention, support, attitudes and counselling. Those studies which have dealt with metaphor and illness have not been based on in-depth, interactive data derived from interviews with patients. There is therefore no clear cut methodology for addressing the question posed in this thesis. Clues for approaching this research in a truly phenomenological fashion emerged from the literature that was reviewed. This methodology is outlined below.

3.1.2 Methodological framework

In order to elucidate the unique, metaphorical meaning in illness experience, it was necessary to enter into the imaginative world of others and observe how they subjectively experienced their illness. As Romanyshyn (1982) points out, 'a factual [objective] account about experience is not wrong. It is only that it is not psychological' (p.86). Phenomenology presented itself as that method which remained open and attentive to the emergence of meaning by remaining faithful to experience on its own terms. Due to its fidelity to immediately felt experience, phenomenology was well suited to the question of this research. Rather than describing the experience of HIV factually, phenomenology remained attentive to what immediately appeared and imaginatively revealed itself.

Acknowledging the essence of phenomenological praxis, the task of the researcher was then to commit herself to the 'rigorous description' of illness, 'contextualized in the *lebenswelt*' (Stones, 1979, p.149). Furthermore, an important methodological objective was to establish a *way of seeing* which opened up a world which mattered, and which must be understood. The following fundamental phenomenological precepts were applied to the data collection and analysis phase of the research and largely guided the parameters of the research.

3.1.2.1 Lifeworld

Phenomenology provides a sustained legitimization of the life world - 'a world constituted through and disclosive of human existence' (Brooke, 1991). To recognise that 'human psychological experience is visible through the things of the world' (Romanyshyn, 1982, p.39), is to perceive the interconnectedness of the dimensions that constitute human existence. In line with Giorgi (1984), 'in the phenomenological viewpoint, the body, world, others and time are differentiable but they are not lived as separate entities' (p.25). Situating experience in the lifeworld and making sense of that experience, entails perceiving these dimensions of human existence as mutually implicative.

If the world is the 'dwelling place of illness' (Van den berg, 1972a, p.130), it is necessary to understand the individual's illness in light of the way he/she embodies him/herself in the world around him/her and in relation to others. Following Van den Berg (1972a), the reality of the patient must be taken completely seriously without the imposition of theory or assumption. The phenomenologist immerses him/herself in how the illness is present to the patient, believing wholeheartedly in the patient's reality. In this instance, the researcher was guided by an ethical obligation to rigorously and systematically describe the experience of HIV from the point of view of each participant, believing wholeheartedly in how HIV was immediately present to them.

3.1.2.2 Description

The phenomenological approach is essentially descriptive rather than explanatory. Explanation does not proceed towards an understanding of experience. Rather, 'it tends to leave the

experience too quickly' (Romanyshyn, 1982, p.137). The phenomenological approach requires that, 'the investigator is to remain true to the facts as they are happening' (Van den Berg, 1972a, p.64), and remain faithful to the concrete dimensions of 'the phenomenon as it appears' (Giorgi, 1976, p.331 cit. in Stones, 1979). Description was then the most appropriate technique for revealing the meaning of the phenomenon under study. Brooke (1991) comments that 'the poet's imagination is an attempt to see accurately what is there and to find precisely the right words to speak what is seen' (p.8). Phenomenology lingers with the experience by describing it, and allows an understanding of it to emerge. The phenomenologist seeks to describe what is happening in a manner which is at all times faithful to the story of the experience. An essential task of the researcher was then to directly describe each individual's story of living with HIV without hastening towards an explanation or interpretation of the subjective account of their experience.

3.1.2.3 Imagistic perception

This research proposes that metaphor provides a point of entry into the lifeworld of those experiencing HIV because we as human beings constitute our realities first and foremost, in an imaginative way. In illness something happens to the body and the way in which one finds oneself situated therein. Hillman (1977) and Kast (1992) regard illness as a way in which one is called back to the body, a way in which the psyche attempts to speak in a magnified and misshapen way about its depths. In order to understand what meaning the body is creating, it is necessary to use poetic tools. To look into imagination we need to look with imagination, ie., imaginatively.

Hillman (1977) asserts that 'to go to the root of human ontology, its truth, essence and nature, one must move in the fictional mode and use poetic tools' (p.36). Understanding psychological life as a metaphorical reality entails assuming imagistic perception and seeing the story within each participant's experience. Through *imagining*, the way in which things appear is deepened - and as Romanyshyn (1982) aptly describes - a domain is entered 'where story rather than fact or idea informs experience and where the imaginal understanding of the human heart supercedes

the empirical understanding of the observing eye and the logical understanding of the human mind' (p.xvi). Understanding how metaphor was embodied and lived out in illness entailed adopting imagistic perception. This implied inquiring into the fantasies that constituted each participant's experience of HIV, and being attuned to the imaginative possibilities within each participant's descriptive story.

If one is to contemplate the qualities that describe the phenomenological attitude, one would see that they essentially embody qualities of the heart. Phenomenology is a way of seeing through the heart. It is hospitable, attentive, receptive, sensitive, tolerant and loyal. Phenomenology is ultimately an authentic stance. It is the liberation of egoic consciousness and the appropriation of a stance which is essentially open and receptive to the voice of soul. It is also marked by a *willingness* to put aside assumptions and prejudices in favour of an attitude of openness to imaginative disclosures.

3.2 Data collection procedure

While phenomenology offers a valid approach to this research, it does not present a specific method of data collection or analysis. Wertz (cit. in Giorgi, 1985) claims that part of the very meaning of phenomenology is not to seize upon a particular method and impose it everywhere, but rather to develop appropriate methods precisely in contact with each unique phenomenon (p.160). Giorgi (1970b) asserts that even those researchers who understand the phenomenological approach have experienced difficulty translating it into praxis in a systematic and sustained manner. In terms of this research, the data collection and explication process were largely guided by Giorgi's (1970a, 1975, 1985) method of psychological-phenomenological research, as well as Brooke (1985), de Koning (1979), Parker (1985), Stones (1979) and Thorpe (1989).

3.2.1 Participants

Nine participants were contacted to take part in the research. It was found that access to individuals living with HIV was limited as very few people were prepared to speak openly about

their illness. The participants that were contacted were chosen because they were open about the fact that they had HIV and they displayed a willingness to speak about their experience. AIDS Training and Information Centre (ATIC) in Port Elizabeth was approached first and three participants were contacted. Thereafter one participant was contacted at Hillcrest AIDS centre in Kwa-Zulu/Natal. A further four participants were then contacted at the National Association for People Living with AIDS (NAPWA) in Durban. One other participant was contacted via E-mail.

3.2.1.1 Ethical Issues

An ethical protocol addressing ethical issues (see appendix A) anticipated throughout the course of investigation, was given to each participant prior to the interviews. Although anonymity and confidentiality formed the basis of the ethical protocol, participants preferred to be acknowledged by name. By sharing their experience, participants felt they would be able to encourage others to be open about HIV/AIDS and thereby work towards a shared understanding of what is still primarily a highly stigmatised disease. Theirs were the voices that could reveal the person behind the statistics that have become so prominent. As one participant commented, "Statistics don't mean anything. Behind every figure there is a person with feelings, that hurts, that cries - that feels."

3.2.2 Interviews

Interviews were firstly conducted with three participants in Port Elizabeth and thereafter with participants in Kwa-Zulu/Natal. To begin with, an introductory interview was conducted with each participant. This consisted of creating a comfortable atmosphere, speaking about the nature and purpose of the research and finding out how the participants felt about participating in such a study.

Upon approaching the data collection phase of the research, the researcher was constantly aware of a certain contradiction or tension. Phenomenology is by its nature open and accommodating.

Whilst inquiring into a given phenomena it stands back in order to invite the revelation of emergent meaning. Phenomenology seeks to minimize any form of imposition upon the phenomenon under question. Ontological and epistemological assumptions which prejudicially affirm, doubt, or otherwise categorise the phenomenon as it primordially appears, are bracketed (Brooke, 1991). Typical areas of phenomenological inquiry include the more commonly understood and clear cut experiences for example: guilt (Brooke, 1983), anxiety (Fischer, 1974), and happiness (Parker, 1986). Individuals are asked to describe a situation in which they experienced feeling guilty, anxious or happy.

The question posed in this research however, required some form of focus and structure. The experience of HIV is not a singular or isolated event. In some cases participants had been living with HIV for more than five years. It was decided that in order to arrive at a meaningful account of the experience of living with HIV, certain questions needed to be asked in order to avoid becoming lost in that which would reveal itself. In effect, an interviewing guide was fashioned, emanating from reviewed phenomenological literature.

3.2.2.1 Interview guide

In order to conduct interviews, an interview guide (as suggested by Kvale, 1996, p129) was followed. The objective of the interview guide was to provide a list of semi-structured questions with which to explore participants' experience of living with HIV. The questions arose out of the literature that was reviewed prior to data collection taking place. A phenomenological explication of illness as posited by Van den Berg (1972a), classifies the patient's complaints into four groups, namely: the changes that take place in a person's relationship with his/her world, others, body and time. These four issues acted as basic themes from which direct questions were generated. By asking the individual to describe how each of these appear to him/her, we begin to see how illness is lived and embodied as a world.

The researcher then aspired to arouse the imaginal dimension of the psyche as much as possible, whilst focusing on the interrelation between body, others, time and world. For example,

participants were asked how they imagined/pictured HIV/AIDS, what images came to them throughout the course of their experience, and how they imagined HIV inside their bodies. Each question was asked with the intention of opening dialogue and discussion between participant and researcher. When participants did not grasp exactly what the question asked of them, questions were slightly rephrased or explained (see figure 1).

WORLD:	- What is living with HIV like for you; how does it feel? - How does the world appear to you on days when you feel particularly sick? - Do you see things differently now that you have HIV?
BODY:	- How do you feel about your body? - Do you feel differently about your body now that you have HIV? - Is your body unable to do the things it once was?
OTHERS:	- Can you tell me about your relationships with others? - How did others respond to you when you were diagnosed with HIV? - How did/do you think other people felt/feel about you? - Are you engaged in an intimate relationship?
TIME:	- How did/does the future appear to you? - How do you feel about death?
HIV/AIDS:	- Did you have a picture/image of HIV/AIDS before you were diagnosed? - If so, can you describe it to me? - How do you imagine HIV; do you have a picture of it? - What images come to you? - Do you ever imagine HIV inside your body?

Figure 1. Interview guide one.

A tape recorded interview was conducted with each participant. Interview material was then subjected to the following procedure; First, each interview was transcribed verbatim. Thereafter protocols were read and re-read in order to gain a holistic grasp of the material and those important metaphors and themes that spontaneously emerged, were underlined.

These metaphors and themes were used to draw up a second interview guide. Questions were formulated to expand upon and clarify the meanings immanent in interview one. (See figure 2 as an example)

In the previous interview you said, "***You can put me in anybody else's body just not mine.***"

- Can you tell me more about that?
- What did that feel like, to want to leave your body?
- Do you still sometimes feel as if you don't want to be in your body anymore?

Earlier you said, "***Whenever I feel sick, I always think that it is the virus that wants me in bed so he can do his dirty work while I am flat on my back.***"

- Can you tell me more about that?
- You speak of the virus as a "he"; if he is a male, what does he look like?

You said that "***...in order to survive the discrimination in the family I had to have a heart of stone.***"

- Can you tell me more about having a heart of stone?
- How did it feel to be discriminated against?

When you first heard that HIV was in your bloodstream you said, "***I imagined I had itchy skin like a lot of ants inside my body biting me.***"

- Can we explore that for a while- tell me more about the ants?
- How did it feel?

Figure 2. Interview guide two.

A second interview was then conducted in order to clarify (ie. deepen and amplify) meaning. Participants were also able to verify whether their articulated experience was effectively grasped and accurately understood by the researcher. The data derived from interview two was subjected to the same procedure as that of interview one. A further two telephonic interviews were conducted with participants three and four in order to once again clarify and expand upon meaning.

An interview and informal conversations were carried out with one participant via E-mail, and a lecture given by this participant was attended. In addition, a tape consisting of this participant's "dialogue" with his virus was obtained and transcribed. This participant's dialogue with HIV was considered an important contribution to the research. It suggested that individuals might establish some form of metaphorical space within which to live with HIV. In effect, this 'dialogue with

HIV' was included as an additional source of data (section 4.3., Chapter Four).

All the transcribed protocols derived from the interviews, were read several times in order to gain an in-depth familiarity with the material. Five protocols were then selected to constitute the study, three transcriptions being omitted. These were omitted because they did not yield sufficient data. Furthermore, two of these were given by individuals who had been diagnosed with HIV for less than a year. It was found that such a short time span could not elicit the depth of experience that the researcher required.

Of the five protocols selected to constitute the study, three were chosen for full phenomenological explication. These protocols were selected due to the richness of the material and the presence of sufficient imagery and metaphor.

3.3 Method of Explication

The body can speak, if we are prepared to listen, with an "authority" which must be respected. (Gendlin. cit. in Levin, 1988)

In order to remain at all times faithful to the phenomenon under study, the analysis section of the research was primarily concerned with *explicating* the data in a manner which allowed the data to speak for itself. Explication in this instance, can be seen as a process of further drawing out and further elucidating the meaning inherent in living with HIV in a way that truly reveals the felt experience of the situation. Part of this phenomenological endeavour is to bring 'the pre-reflective life-world ... to the level of reflective awareness where it manifests itself as psychological meaning' (Valle and King, 1978, p.17). Yet, Van den Berg (1972a) comments that 'to arrive at an explanation of pre-reflective matters ... one has to abandon the usual way of thinking' (p.75). One has to make the problem speak for itself. It was with this attitude in mind, that the explication phase of the research ensued.

The three selected protocols were individually explicated using the following steps:

3.3.1 Holistic grasp of the data

The chosen transcripts were read and re-read in order to achieve a comprehensive, intuitive and holistic familiarity with the data. At this stage it was necessary to bracket presuppositions and preconceptions which might have imposed upon the data's capacity to speak for itself.

3.3.2 Delineation of meaning units

To render the protocols more manageable, each original protocol was then broken down into naturally occurring units which emerged spontaneously from the data. Natural Meaning Units (NMU's) are essentially discriminations within a participant's descriptive protocol. Each NMU serves to demarcate the transitions from one nuance of meaning to another within each participant's description of his/her experience.

The NMU's resulting from this step appear in the left hand column of section 4.1., in the results chapter of this study.

3.3.3 Re-articulation from a psychological perspective

Each NMU, expressed directly in the concrete, every-day language of the participants, was systematically interrogated through a process of reflection and imaginative variation. (Giorgi, 1985; Wertz, 1983). By reflecting upon the imagined possibilities in each sense unit, it was possible to re - articulate each NMU in a psychological manner and in a way that accurately expressed the participants' intended meaning. According to de Koning (1979), 'this step is recognised as the crucial hermeneutic step in which the subject's particular experience is reduced to the level of essence, and his own language is transformed into the language of psychological science' (p.124).

The transformed meaning units arising from this step appear in the right hand column of section 4.1., in the results chapter of this study.

3.3.4. Case Synopses

Following Wertz (1985), the delineated meaning units were thematisized according to their intertwining meanings and placed in a way that accurately reflected the pattern of participants' experience over a period of time. Unnecessary and repetitive material was eliminated. The regrouped and transformed meaning units were then synthesised and integrated into a coherent description of the experience of HIV for each participant. Each case synopsis remains faithful to each participant's unique lived experience of HIV. It further accurately reflects the experience of HIV as it unfolds over a period of time.

Kirmayer (1992) points out that 'the bodily grounding of metaphor provides modes of thinking that yield rich, yet often hidden meanings' (p.335). Case synopses were thus fairly expansive in order to maintain an openness to the imaginative possibilities inherent in participants' descriptions. In other words, to capture the uniqueness of each individual's imaginal world.

3.3.5 Reading of additional protocols and 'dialogue with HIV'

After constructing case synopses, the remaining two protocols were read and re-read. The aim of this process was to extract further data which could add to, support and clarify the themes and metaphors emerging from the three fully explicated protocols. These two original transcripts were broken down into NMU's in order to delineate relevant themes, yet they were not subjected to full phenomenological explication. They can be found in the appendices

The transcribed information derived from one participant's audio tape recording of his 'dialogue with HIV' was then read, and included in the results section of the research as an additional source of data.

3.3.6 Extended Description

An Extended Description of the general structure of the experience of HIV was then constructed by the researcher. The situated case synopses were read and re-read, as well as the information derived from reading the additional protocols and the 'dialogue with HIV' until common

metaphors and themes emerged. During this phase of description, all the original protocols were constantly referred to in order to validate what emerged to be important in the experience of living with HIV. The Extended Description translates into an essential, integrated and meaningful structure of the experience of HIV.

3.3.7 General Structure

Following Brooke (1985), the researcher summarised the Extended Description and constructed a general or essential structure of the experience of HIV. The Extended Description was read a number of times until a succinct rendering of the experience of HIV emerged. Following Thorpe (1989), the general or essential structure contains the necessary and sufficient conditions, constituents and structural relations which constitute the experience of living with HIV. This summary offers a psychological definition of the experience of HIV which may be of use to psychologists.

CHAPTER FOUR

RESULTS

In the following chapter the results of this study are presented. In order to illustrate the method of this research, one participant's (Sarah) explicatory process is fully documented. Firstly, Sarah's original interview transcript, grouped into NMU's (left hand column) and rearticulated in psychological language (right hand column), is presented. This displays the first and second step (discussed in section 3.3.2 and 3.3.3 of Chapter Three) of the phenomenological explication. A case synopsis describing Sarah's concrete, situated experience of living with HIV is then documented (section 3.3.4 of Chapter Three) followed by Diane and Pat's case synopses. David's synopsis accompanied by his dialogue with HIV is then included. A synthesis of the themes gleaned from all participants then appears in an Extended Description (section 3.3.6). Following this, a General or essential structure (section 3.3.7) is presented which offers a succinct definition of the experience of living with HIV. Finally, three tables are included which present the salient metaphors and images which characterised participants' experience.

4.1. Sarah: Organization of data

Sarah is a coloured female. She was diagnosed with HIV in 1992. Sarah remains very active in the AIDS awareness field, working at AIDS Information and Training Centre (ATIC).

Can you tell me when you were diagnosed with HIV.

1) I was diagnosed in 1992 as having HIV. I had a blood transfusion in 1988. I think it was sexually transmitted but I did have a blood transfusion in 1988 and I never had the courage to go back and check whose blood it was. But I mean 98% of all cases are sexually transmitted. Very few are from blood.

Lacking the courage to ascertain details of her blood transfusion, Sarah was unable to establish the exact manner in which she contracted HIV. She assumed that the virus was sexually transmitted.

2) When I was first diagnosed, the doctor diagnosed me with cancer. I knew that people with cancer die. I thought; what if I die here? The kids will have to run up and down to get the corpse buried. I moved house. In December 1992 I came home to Port Elizabeth. I actually came home to die. I didn't want to give my family that much trouble because the body will be there and they will be living here. So either they transport the body back here - the corpse - or they have to go up there. So I moved closer.

3) Then they said one more test and they never told me which test. I remember going to the hospital for three days. I sit there for the whole day and they don't tell you a thing. At four they say, "Come back tomorrow." This went on for two and a half days. On the third day I was so furious. I said, "This is it. I demand to know what is wrong with me."

4) I think they were scared, they didn't know how to tell me. The doctor finally said to me, "I am sorry to tell you this but you've got AIDS."

Sarah was initially diagnosed with cancer. She was subsequently confronted with the practicalities of the death of her physical body. Fearing being a burden to her family, Sarah returned home in order to alleviate any complications that may have ensued apropos the burial of her body.

Sarah experienced anger and frustration upon awaiting her second diagnosis. She perceived others as being secretive and incompetent. They appeared hesitant to disclose her results. Sarah finally demanded to be informed of her results.

Sarah attributed this secrecy and hesitancy to the hospital staff's inability to find an effective means of informing her of her diagnosis. She was eventually informed by the doctor that she had AIDS.

Can you describe to me how you felt at that moment.

5) While I was sitting there and the doctor said I had AIDS - he didn't even say HIV - there's a lot of things to think about in that split second when he said that word. The first thing that I thought is; he's not talking to me, there must be another person in the room because other people get AIDS and HIV but not me.

6) Then it just hit me. I remember sitting there with my brain working like a tape recorder. Two buttons on the tape - rewind and fast forward. I press the rewind button in my brain to work out where it happened, why it happened, why me?, and then I used the fast forward button to say what am I going to do now?, where do I go to from here?, what do people with AIDS do?, people with AIDS die - I have no life. And I remember sitting there with these backwards and forwards thoughts - confusion, back and forth, back and forth, it's playing back and forth the whole time.

7) I remember when I came out of the hospital I saw this woman - one of the

Upon informing Sarah of her results, the doctor failed to differentiate between AIDS and HIV. Sarah was confronted with a plethora of thoughts upon hearing her diagnosis the first of which were disbelief and denial. She could not believe she had HIV because she identified AIDS as a disease affecting other people.

The reality of the doctor's words was immediately transformed into an incessant dialogue within Sarah's brain. Sarah's image of the tape - recorder introduces the issue of time and reflects her attempt to give order to the immense confusion and panic she felt. An inquiry into her past sought to make sense of and establish responsibility for her present predicament. Sarah equated the future with a feeling of meaninglessness, the only certainty being death.

Sarah's fear and anxiety translated into an immediate desire to escape her body. Sarah's

domestic workers. She was mopping the floors and I remember that I was so terrified and I looked at her and I said, "God - why did you have to let me get it, why couldn't you give it to her?" I was bargaining with him. I was willing to be anybody else, I didn't want to be me. If only I could get out, jump into anybody else's body - that would be fine - but it didn't happen. In some way I was blaming God, accusing him as well; "What kind of God are you? Why do you let this happen to me? You said you would never leave me."

8) When I was first diagnosed with HIV I was uneducated HIV wise. I didn't know anything. The only thing I knew was that with HIV you're going to die. I didn't know when am I going to die - tomorrow, next week - a year - how much time do I have to live? I was very scared, most of all I was very scared. I was really confused and I was shattered. It's scary when you don't know the facts about HIV.

Did you have a picture or image of HIV before you were diagnosed with the virus?

9) Yes. When I first heard the words AIDS I pictured death, a big black coffin and I

accusatory appeal to God reflected her feelings of injustice, anger, betrayal and abandonment. She perceived God as being responsible for her present situation.

Sarah's initial ignorance regarding HIV inspired in her a feeling of fear. She perceived HIV as being synonymous with death and she was absorbed by feelings of anxiety, confusion and uncertainty as to when she would die.

Prior to being diagnosed with HIV, Sarah had appropriated an image/picture of AIDS from

mean that big black coffin. The only advert of AIDS that I saw in those years was this big, black coffin with people busy burying that AIDS person. The first thing that came to my mind was darkness and the big black coffin. I was very scared.

10) You can go to jail for murder, poisoning, attempted murder, for infecting another person, that's what I imagined. There's no law that protects the people that are being infected. Infecting someone with HIV is like poisoning someone - it could be murder or attempted murder. That's what I thought.

11) I was very scared to sleep at night because AIDS kills they said. I didn't know when it was going to come, when death is going to come. It might come when I was still asleep. Will it crawl up on me? I didn't know where it was going to come from. Am I going to die in three months time?

12) I used to wake up in the middle of the night and run to the window and check whether I'm still here down on earth or whether I'd moved to some other place.

13) I still felt I had a lot of things to do. I

the media. This image imparted a sensationalised and fatalistic message of the disease which evoked fear in Sarah.

Sarah imagined the act of transmitting HIV to be synonymous with a criminal offence, which could result in imprisonment.

An anonymous other(s) propagates the metaphor of AIDS as death. The inevitability of her impending death and uncertainty of remaining life evokes feelings of fear and anxiety in Sarah. Death is depicted as a mysterious and unpredictable visitor.

Sarah's fear and anxiety was manifest in her inability to comfortably inhabit her body. She would wake to see if she was still embodied on the earth.

For Sarah, the present was equated with a

couldn't plan. I couldn't even see tomorrow. If I had to think about tomorrow it was kind of dark, down there. I couldn't picture it. I thought that I had no future because of AIDS. The future was cut off. I couldn't see anything out there.

Did you ever picture or imagine HIV in your body?

14) In the beginning I had a picture of HIV but now my picture has faded. At one stage I imagined I had itchy skin, like a lot of ants inside my body biting me. Some doctor said it's my imagination because I know that HIV is in my blood stream. He said I'm imagining that something is eating me, but there was nothing eating me. I could feel them actually crawling, these thousands and thousands of ants eating me. I thought that this is what the virus should look like because they say it is destroying me from the inside. That is what my picture looked like.

15) Thinking about the ants in my body - it all has to do with what state my mind was in. In the beginning I was scared because of HIV, the way I'm going to die, what am I going to look like? I had no basic education

variety of tasks which still needed to be completed. The future however, appeared inaccessible to her. An inaccessible future imparted a sense of meaninglessness.

In the initial stages of living with HIV, Sarah imaginatively experienced the virus as thousands of feasting ants inside her body. Sarah's imaginative perception of HIV was shaped by an anonymous mass understanding of the disease - defining HIV as an invasive force destroying life.

Sarah believed that her fear and ignorance of HIV shaped her imaginative perception and experience of the virus.

with HIV when I was diagnosed. I knew nothing.

16) With every tick, with every beat of my heart I actually realise that my life is getting shorter. Every tick is one gone, one gone, it's going, it's going, it's going every day, day by day. It was something like a clock inside my body.

17) I don't like to think about it a lot. Most of the time I try not to think about it because we all have to die one day. I try not to think too much of what is going to happen in a few years time. I think the main thing to do is to live every day as if it's the first day of my life. It's very important that I concentrate on what I'm doing now. I don't think about tomorrow.

18) If I plan too many things I get to a stage where I can't plan any further. I don't think about death that much because I think if I think about death - I can actually go hysterical. I don't try to paint myself a picture of what I'm going to look like. I try to say to people that I'm not going to worry about that now. I'll worry about that when I get there. If I worry about that now, then I'm

Sarah experienced an acute sense of urgency and anxiety, and was absorbed by a preoccupation with time. This sense of urgency was imaginatively mediated through the image of a clock.

Sarah prefers to focus on the present rather than preoccupying herself with the future. This translates into a decisive dedication to living one day at a time.

Sarah avoids contemplating her future and death. This would engender anxiety which would contribute towards stress and illness.

going to get sick. It's not even my problem yet, it's still to come, so I'm not going to bother about it. I'm not thinking too far.

19) Counselling really helped. I received counselling straight after I was diagnosed and I got educated. I remember my main concern then, was what am I going to look like?, because I had a scary picture of AIDS. I thought of the ugly way you can die. I was scared about the way I would look. The counsellor explained. I wanted to know the signs and symptoms. I wanted to know - what am I going to look like when I die? I demanded to know everything about AIDS and HIV in one day. After that I felt better because I knew HIV and AIDS weren't the same thing. I then disappeared for about seven months. That's when I went through things like rejection and discrimination.

Can you tell me about that.

20) There was so much discrimination that when I walked up the street people tended to shift to one side, they kept away. People used to gossip about me - even my own family. My mom made it her duty to tell everyone I had AIDS. If I had a cup of tea my mom would tell the children you can't

Sarah's fantasy of HIV, as synonymous with AIDS and death, engendered in her feelings of anxiety and fear regarding physical disfigurement. Much of this fear and anxiety was alleviated after differentiating between AIDS and HIV.

Her community and families ignorance and fear of contamination regarding HIV, left Sarah spurned and humiliated.

share that cup because I had AIDS. She told them things like they couldn't sleep next to me because my sweat will infect them. They would almost dust the chair when I got up because they didn't feel like sitting there after me. It was honestly dreadful

21) Then one day I said, this is it! They're discriminating against me, I will show them. Because there was a lot of discrimination against me I decided to go public. It's a difficult decision to take because others can torture me.

22) I went public because I wanted revenge. People didn't want to accept me and I thought; I'll make you accept me, you will have to know me.

23) My mom thought "Ooh it's a scandal" because I had HIV and in the meantime she went around and told all her friends and they were gossiping about me. So I said, "You don't have to go around anymore, I'm going to the newspaper and I'm going to tell them I have HIV and then each one of your friends can just buy a paper and read it, it saves you the trouble."

The discrimination Sarah experienced inspired feelings of hurt and anger and in turn motivated her to punish those who had humiliated her.

Sarah's decision to go public constituted a challenge and an assertion of her right to be acknowledged.

Reacting against the hypocrisy in her community, Sarah decided to expose her story to the media.

24) I was so hurt and I think it was because of the hurt that I say coming out of the closet was an act of revenge. They were hurting me so much that I wanted to hurt them too. So by going public, I will tell all the people that I have HIV and they can feel what I felt like.

Did going public help you...?

25) I think what helped me the most was being public and being able to talk about it, being open. Not talking to anyone, you can be dead in two years. It becomes too much of a stressful life and stress kills, keeping something inside which needs to be shared. It's not actually HIV that kills it's stress because of discrimination, it's depression.

26) When I went public I was able to share my status with others and I found other people with HIV could be supportive. They knew how I was feeling and that made me feel better. It made me think, "It's not so bad, there's also others like me."

So you felt supported?

27) Yes, but to survive the discrimination in the family I had to have a heart of stone. I mean I had to switch off - like a little

Sarah attributes her desire for revenge to the immense hurt she experienced.

Sarah believes the process of sharing helps to alleviate the stress and depression often accompanying the experience of HIV.

When Sarah went public she encountered empathy and support and was able to perceive her similarity to others.

Sarah describes herself as having a "heart of stone" to ensure her survival amidst a climate of discrimination and rejection. She attained

button - I switch it off. I have that feeling - I feel nothing. I had to have a heart of stone because I almost had to feel nothing to survive. I just decided one day I will never cry again.

28) I also have a very positive brainwave. I believe that getting sick is also in the mind - the mind plays a big role in getting sick. Sometimes when I'm lazy I don't know if I'm sick or not. I don't feel like getting up and going to work. But with HIV if I stay in bed I'll be weaker tomorrow. Whenever I get sick I always think that it is the virus that wants me in bed so that he can do his dirty work while I am flat on my back. I jump out of bed even when I'm sick. I fight.

29) While I'm lying down I don't know exactly what is happening but my immune system goes down further because I'm in bed and thinking negative things like death. I think, "Is this it, is this the end?, am I going to recover?" I think if I don't have to stay in bed and think about death it's better. If I stay in bed and I'm ill I can't think positive things. Whatever stress I have lowers my immune system and I'll lie there suffering from stress and getting weaker and

this state by appropriating an emotional indifference.

Sarah believes that effectively controlling HIV entails possessing a strong and positive mental attitude. When she feels ill, Sarah feels vulnerable and confused and imagines that HIV is deliberately deceiving her. This inspires her to fight HIV by refusing to give in to her illness.

When Sarah yields to her illness she begins to feel anxious and is preoccupied with death. This diminishes her strength and leads to stress.

weaker.

30) The best way to fight the virus is with the mind. So I think about things that will make me get up. I think; I better get up now otherwise the virus is going to kill me, it's going to get me in bed and it's going to keep me there, so I must get up and I must go. It works.

In an earlier interview you mentioned that others can torture you? How does that feel?

31) Stripped naked, then being lashed. Three weeks ago we went to this factory outside PE and this guy said (after I had told the whole group that I was HIV) that people with HIV need to be shot because they are dogs. He said if he ever came across someone who had HIV then he'd shoot it. And at that moment I really felt like a dog.

You said that "In order to survive the discrimination in the family I had to have a heart of stone." Can you tell me about having a heart of stone?

32) Yes I've got a heart of stone. Because there was such a lot of hurt I actually closed up. Feelings are in the background. Not to

Sarah challenges herself to think positively and employs a specific mental procedure to avoid relinquishing her control over HIV. HIV is depicted as a predator, seeking out its victim.

When giving educative talks to the community, Sarah at times feels persecuted, degraded and humiliated.

Sarah defended herself against the hurt she experienced by closing off her emotional world. Having a heart of stone implies an

say that I don't feel anything for everybody. As far as hurt is concerned - I don't feel that there is anything that can hurt me. I'm completely switched off.

emotional indifference

Switched off?

33) Yes. It didn't happen all in one day. It's like building yourself a concrete wall and I don't allow anyone inside that wall.

The process of cultivating an emotional indifference is likened to constructing a concrete wall. Others are prohibited from entering Sarah's world.

34) I don't have a boyfriend and I believe that one of the reasons is because I've closed up. Not to say I don't socialise and go out - I do. I believe that if I fall in love then I will become weak. People who fall in love tend to be hurt too easily.

Sarah avoids intimate relationships because they constitute a potential invasion and threat to her private world. Falling in love exposes one to the possibility of hurt and implies a sense of vulnerability.

35) I won't allow someone to break through that wall and I don't want anybody there because that's my private property. I don't want anybody on the other side of that wall. My body is a private place for me.

She refuses to surrender to the threat of invasion. Others are prohibited from entering her world and she perceives of her body as a private place.

Does the wall break down?

36) Yes. I don't want holes in my wall, it must just stay like that. If I have a relationship I won't be able to go on with

Sarah perceives an intimate relationship as a disruption to her present educative intentions. They may potentially render her vulnerable and

what I'm doing now. I won't be able to face all the audiences that I've got because there will be a little crack there. I don't want a crack there, I just want it as solid as it is now. Relationships will make me a weaker person.

Weaker?

37) Softer, a softer person. If I'm in a relationship you have a soft heart or a soft spot for someone. I won't allow that to happen

So would you say living positively with HIV means having that heart of stone?

38) I have to for me. It's better that way. My body stays strong and whatever they say doesn't really bother me. If what they said bothered me then I would cry every ten minutes and if I cry then my immune system goes down every time I cry. That's what I can't afford. If I cry every time they say something I'm going to cry my whole life and I'm going to die because I'm going to suffer from stress.

39) I have a lot of friends who understand me and I have a great time, but no place for

defenceless.

For Sarah, an intimate relationship implies a dissipation of strength and a degree of vulnerability which she will not tolerate.

Having a heart of stone preserves Sarah's strength and emotional indifference. This appears vital in order to ensure survival.

Sarah will not allow intimate love to enter her heart.

love behind my wall.

It seems as if others are “out” there and you are “in” here?

40) I would say yes. It feels like that. A lot of people can't understand what it is that keeps me going. Sometimes I don't even know what it is that keeps me going. Maybe it's the brick wall - it protects me from the outside.

Sarah's wall serves to demarcate a boundary between herself and the outside world which protects and distances her from others.

You said that coming out of the closet was an act of revenge?

41) Yes. My family didn't want to be associated with me. My act of revenge was something showing them; You don't want to know me today but I will bring you down to my level - you have degraded me to the lowest level - I'll take you down there with me.

Sarah's anger and hurt manifested in a desire to expose her family to the humiliation she experienced at their hands.

Was it an attempt to be noticed?

42) In some ways yes. Because I am so bad and low, no-one wanted to be associated with me. I was ignored and could have been forgotten. I thought that I must make them know me again. I refuse to be ignored.

Sarah's act of revenge was an attempt to assert her existence amidst a climate of rejection and ostracism.

43) Because I have HIV I am very low

Sarah's community conceptualise HIV as a

because in society today when you've got HIV they think you've done something wrong. First of all you must have had many partners or be homosexual or a prostitute in the street; you were doing all the wrong things.

44) Because I had HIV, those were all the things I had done so now I'm at the lowest level. They didn't want to be associated with me.

You did mention that going public was helpful.

45) Yes because I met other people with HIV and AIDS and this made me feel better, like I wasn't on my own so much. You know it can be a lonely thing, but I didn't feel so lonely with others who knew what it was like. This also made me feel that I must work to make other people accept us with HIV.

When you were first diagnosed you said that you wanted to be in anybody else's body just not your own, you wanted to "jump out".

46) If I could escape my body and leave it that day I would have. I didn't want to be

disease afflicting sexually deviant individuals. Individuals are judged by the community and found guilty of transgressing a moral code.

Labelled as a sexual deviant, Sarah was degraded and ostracised.

Meeting other people with HIV enabled Sarah to perceive her similarity to others which alleviated much of the loneliness she felt. Others lent empathy and support to Sarah. This motivated Sarah to work towards making others accept HIV infected individuals.

HIV posed a threat to Sarah because it implied death. Her fear of HIV impaired her ability to

me. I didn't care in whose body I jumped. I didn't want my body anymore because I think I was scared. My body felt strange to me because I had HIV. I was scared - HIV kills. That's the only thing I knew then - it kills.

47) I didn't know when I am going to die, how I was going to die. I think I was more trying to escape death because I wasn't ready. I'm not ready for this - it came too quick. I wanted to leave this body behind because honestly I wasn't ready to go.

Did you feel death in your body?

48) Yes. Like some nights I was waking up sweaty or wet, running to the window, checking; did I move to another place or am I still here? It might sound stupid but I did. I didn't know where it's going to come from. Will it come at night when I'm asleep? Will it crawl up on me? I still felt I had a lot of things to do.

So you realised your body...

49) It was useless to me because it was full of HIV and not HIV for that matter remember the doctor said AIDS. As far as I was concerned it was full of AIDS. I just

authentically relate to and inhabit her body. Her body felt alien to her.

Sarah's body implied limitation to her because it harboured the threat of death. Sarah felt she was not yet prepared for death.

Sarah's preoccupation with death left her feeling fearful and anxious. Her fear and anxiety manifested in a failure to comfortably inhabit her body and world. Death is once again depicted as a mysterious and unpredictable visitor.

Sarah felt that her body had no more function anymore since it was riddled with AIDS. The image of the old shoes reflects Sarah's feelings of ambivalence towards her body.

wanted to get rid of it. Like an old pair of shoes you don't see the need of wearing them anymore - you just get yourself a new pair and leave this pair behind.

You said that sometimes with every beat of your heart there was a tick - your life getting shorter?

50) Yes I would say that it was just with every beat of my heart it seemed as if one day nearer to the grave, one beat nearer to the grave, getting closer and closer. At some stages I almost felt as if I could let it stop for a while then I could live longer. If it just didn't go that fast - slow it down.

When you first heard that HIV was in your bloodstream you said that, "I imagined I had itchy skin like a lot of ants inside my body biting me." Can you tell me about the ants in your body and how it felt.

51) That was just after I was diagnosed. It had to do a lot with infected blood. I went for counselling and they explained that HIV was in my bloodstream. I think it was then that I had these things like thousands and thousands of ants eating me all the time. It was on the inside like things biting me. I think it was my imagination - it went on its

Sarah's urgent and pronounced heartbeat signified the embodiment of her preoccupation with time and death.

Sarah imaginatively perceived HIV as thousands of ants devouring her.

own. I imagined myself seeing these things eating me, taking over me.

You weren't in control?

52) I wasn't in control. The ants were going mad especially in my legs.

Sarah experienced a loss of control.

What did the ants look like?

53) I imagined they were black because if they were red ants they would have jumped. They are more vicious - the red ones. I just saw these black ants eating the blood inside. It was my way of seeing the HIV virus eating in my blood. The black ants were trying to kill me because AIDS kills, feasting and taking over. Maybe I thought that they were coming to kill me now.

The ants were imaginatively perceived as black, infesting her blood. They signified the consuming quality of HIV, intent on immediate destruction.

Do you still feel like you sometimes wish to leave your body?

54) No, I'm quite comfortable with my body now. The main thing I need to do, is to get my body to work with me to survive. That's the only thing I work for - to survive as long as possible.

After harbouring a desire to escape her body, Sarah now feels she inhabits her body in a comfortable fashion. Sarah feels that a harmonious relationship with her body will ensure survival.

55) They say if you love your virus then it is much easier. They say you shouldn't hate the person who infected you because then

An anonymous other prescribes to Sarah a potentially effective means of living with HIV. This entails establishing a relationship with

it's stressful and your immune system goes down. As soon as you learn to love HIV, make peace with it, then HIV is very good for you.

56) This is how I do it. HIV works with me, I don't see it as an enemy. If I had to sit and think that, I would think things like - I hate HIV and what HIV is doing to me, I hate the person who infected me. I used to think like that and it would be stressful and within two years time I would have been dead.

So you make the virus work with you?

57) Yes, I don't see it as an enemy. I wouldn't actually say I've befriended my virus. Rather I love my virus, it's *my* virus.

58) There's a lot of things my virus does for me. My virus looks after me and my virus is one of the things that got me a job. He looks after me and I look after him. Whenever I'm sick I go to the doctor. If I didn't have HIV then I wouldn't go to the hospital that frequently. That's my little voice that tells me or reminds me that I must go. HIV says, "I'm here, if you don't look after me then I'm going to kill you." So I've got to go to the doctor and tell him what is wrong with

HIV based on love and acceptance.

Sarah appropriates this attitude of love and acceptance towards HIV. Sarah believes that relating to HIV as an enemy results in stress.

Sarah's relationship with HIV is characterised by love in which she fully appropriates HIV as her own.

Sarah's relationship with HIV is based on a shared investment in their mutual need to survive. HIV is depicted as a voice of conscience, reminding Sarah to care for herself.

me so HIV can live in me. If I die, HIV dies too - both of us are going to die. I want to live longer with it.

Sometimes you say you have to fight your virus.

59) Especially when I'm tired. Sometimes I'm tired of fighting society, and then I've got this virus inside me and I've got to fight it too, and I want to give up saying, "I don't care anymore, I'm tired." And a lot of times I do feel like that lately.

60) What really keeps me going is that there have been many people with AIDS before me. They have been in this war fighting AIDS. I mean the terrible discrimination of AIDS people. I want to carry on what they have been doing. I always tell them that if only I can find another woman - not a man - who's willing to do what I'm doing, then I can go to sleep nicely on my bed and wait to die because I'm tired. But until that person comes along I cannot go. I prefer a woman. When it's a man the community tend to think it's a homosexual disease and if it's a woman there are things like women's rights. A woman has very little rights in whatever community she lives and I would feel that if

Sarah perceives herself as fighting two forces; the discrimination surrounding HIV/AIDS and HIV itself.

Sarah's motivation for fighting the discrimination marking AIDS is inspired by previous AIDS sufferers. She feels she cannot relinquish her role as fighter and educator until she finds a significant female who will continue with her educative intentions. Women make an important contribution to AIDS work because they attend to matters such as women's rights and abandoned HIV- infected children.

it's a woman she would look after the others, speak for abandoned babies. Males don't do that.

61) Sometimes I have to fight HIV. There are many things he does for me - he's very unpredictable. HIV can make me lazy. Sometimes he's so naughty that he actually wants me to stay in bed and he'll even tell me, "You've got a backache today" and I'll convince myself I've got a backache. But then I think maybe he wants me to stay in bed so he can do his dirty work while I am flat on my back and bring my immune system down. With HIV if I stay one day in bed I'll be weaker tomorrow. The longer I stay in bed the lower my immune system goes. He can be quite evil sometimes. But most of the time I control him. I can control him, he can't control me. I fight.

You speak about being "in this war fighting AIDS" ... is that the role within which you see yourself?

62) Yes. It's fighting all the discrimination around us people living with HIV. It's also teaching people about AIDS and HIV. My ambition is to educate other people about HIV and AIDS. I would hate to see someone

Sarah perceives HIV as a trickster. He is at times manipulative and capricious. Sarah must make a decisive and sustained effort to maintain control over HIV. This entails acknowledging HIV's deceitful, unpredictable and manipulative nature and asserting her control over the virus.

Sarah defines her present role as educator and fighter. Education is imperative because the severity of the AIDS pandemic is intensifying. She feels challenged when people discriminate against her because it provides an opportunity

infected. Teaching others is important. They say this is the AIDS generation now, most of the teenage girls are pregnant. They have babies that are HIV. The teenagers and the babies are going to die. I don't know who will be here after 2000. If I can save one soul - if I know one person would listen - then it's fine with me. For me it's a challenge when people discriminate against me because then I can educate them.

to educate them.

So you feel motivated to...

63) Motivated - yes. I want to teach other people about this disease so that all this discrimination stops - or maybe people will understand HIV more. Another important thing besides education is listening to people who are sick. The government put a lot of money into education and prevention but there's very little being done about the person itself. They are educating but in the meantime more people become sick. Why don't they look after the people who are infected now? Why are we HIV people not listened to - we must be heard.

Sarah is motivated to educate others about HIV/AIDS in order to counteract the discrimination and ignorance which marks the disease. Sarah feels the government places more emphasis on education and prevention strategies than attending to those who are ill. Sarah believes those with HIV must be listened to and heard.

You say you have a very "positive brainwave"?

64) I do control my body with my mind. Like

Sarah effectively deals with pain by possessing

when I've got headaches or pains and aches, I will control it with my mind. I will tell my body that there's nothing wrong with me and that I am imagining to myself that I am feeling pain. I can feel the pain but I just work it from my mind. I can control pain with my mind. I just have to concentrate on it. I believe that every thing you tell yourself will happen to you. Whatever pain I have I tell myself I am imagining it, it's not there, it's just because of HIV that I'm thinking that I've got a headache. I convince myself that I don't have a headache and it will go away

Earlier you said, "Whenever I feel sick I always think that it is the virus that wants me in bed so he can do his dirty work while I am flat on my back." You always refer to HIV as a "he".

65) I think he's a man. I don't think he's a woman. I think because the image that men have - they are in control. Somehow I can manage HIV, I can control it, but HIV's stronger than my body so I think it's a man. Men are dominating creatures as well, they like to overpower. They want to be the strongest and are very demanding. Females are not like that.

a strong and positive mental attitude.

Sarah imaginatively perceives HIV as a male. The qualities she defines as masculine; power, strength, control and domination, are attributed to HIV.

What does he look like?

66) I only know that he is wearing black. I think he's very huge. If I had to put him in a human body he's about seven feet tall and he's built very hefty and when I think about it he's always laughing - not smiling, laughing as if he's teasing. Mocking, that's the way I see him. His mouth is always open, laughing, something like, "I've got you, you can't get rid of me, I've got you." But then he's not so bad, could have been worse. People used to live two/three years then they used to die. Now they're living longer with HIV.

Earlier you mentioned the virus crawling in at night...?

67) Like the one with the many legs you get in the sea - octopus. It clings to you and doesn't let you go, it stays there. In the beginning it was claustrophobic. It still looks like that. But I think then I thought it was like attacking me. I was scared of it because I knew it kills.

68) It's still here with me and it's still holding on. The only time it lets go is when you kill it. You can't just pull it off. You have to kill it so that it can let go. HIV's not

Sarah visualises HIV as a large, overpowering man cloaked in black. He assumes a ridiculing, taunting and antagonising stance, asserting his control over Sarah.

In the early stages of her diagnosis, Sarah was fearful of HIV and imaginatively perceived the virus as an octopus. This image reflects HIV as an oppressive, suffocating force which desires to kill.

HIV continues to have an inextricable hold on Sarah.

killed yet. It's still there clinging.

Do you feel you have changed as a person having HIV?

69) I would say yes. I appreciate life. Things that I would never notice, I will notice now.

Sarah feels she has a deeper awareness of, and appreciation of life.

Like?

70) Like I can live in a street for years and that tree has always been there and I never noticed it. But after I was diagnosed with HIV, that tree out there I noticed. In the beginning it wasn't so beautiful to me but it looks beautiful now. I'm more aware of things around me. The smaller things are important. Feelings of life have changed a lot. I used to take it for granted. I appreciate life more because I know I don't have a lot of time. I have a short time so there are all these things I have to do.

An acknowledgement of finitude implies a heightened dedication to the present. Sarah feels that she is more aware of things around her. Things that were once barely noticeable now appear beautiful.

71) If I can do anything for others I will, especially a person who has HIV. I am much more concerned about other people now. Sometimes I go out and wash people who are sick because their families don't want to touch them. I go out and tell mothers that their daughters have HIV. Sometimes I have to accommodate people with HIV for one or

Sarah displays an attitude of benevolence and responsiveness to others. She feels she is far more concerned for others and especially helps and accommodates people living with HIV.

two nights because they are kicked out by the whole family.

4.2 Case Synopses

4.2.1 Case Synopsis for Sarah

Presented below is a description of Sarah's concrete, situated experience of HIV, followed by Diane and Pat's individual case synopses.

Lacking the courage to ascertain details of her blood transfusion, Sarah was unable to establish the exact manner in which she contracted HIV. She assumed that the virus was sexually transmitted.

Prior to being diagnosed with HIV, Sarah had appropriated an image/picture of AIDS from the media. This image imparted a sensationalised and fatalistic message of the disease which evoked fear in Sarah. Sarah also imagined the act of transmitting HIV to be synonymous with a criminal offence, which could result in imprisonment.

Sarah experienced anger and frustration while awaiting her diagnosis. She perceived others as being secretive and incompetent. They appeared hesitant to disclose her results. Sarah attributed this secrecy and hesitancy to the hospital staffs' inability to find an effective means of informing her of her diagnosis. She was informed by a doctor, who failed to differentiate between AIDS and HIV, that she had AIDS.

Sarah was immediately confronted with a plethora of thoughts upon hearing her diagnosis, the first of which were disbelief and denial. She could not believe she had HIV because she identified AIDS as a disease affecting other people. The reality of the doctor's words was immediately transformed into an incessant dialogue within Sarah's brain. Sarah's image of the tape - recorder introduces the issue of time and reflects her attempt to give order to the immense

confusion and panic she felt. An inquiry into her past sought to make sense of and establish responsibility for her present predicament. Sarah equated the future with a feeling of meaninglessness, the only certainty being death.

Sarah's initial ignorance regarding HIV inspired in her a feeling of fear. Her fantasy of HIV as being synonymous with AIDS and death was shaped and affirmed by anonymous others. Sarah's initial experience of HIV was lived primarily as an isolated existence in which she was absorbed by feelings of anxiety, confusion and uncertainty as to when she would die, as well as a profound fear regarding physical disfigurement. Sarah accused God of being responsible for her present situation. She was pervaded by feelings of injustice, anger, betrayal and abandonment. Much of this fear and anxiety was alleviated after differentiating between HIV and AIDS.

Sarah's fear and anxiety translated into an immediate desire to escape her body. Her fear of HIV impaired her ability to authentically relate to and inhabit her body. Her body felt alien to her and implied limitation to her because it harboured the threat of death. At night Sarah would wake to see if she was still embodied on the earth. She imagined death as a mysterious and unpredictable visitor.

Fearful and ignorant of HIV, Sarah imaginatively perceived and experienced the virus as thousands of feasting ants inside her body. Sarah's imaginative perception of HIV was shaped by an anonymous mass understanding of the disease - defining HIV as an invasive force destroying life. The ants were imaginatively perceived as black, infesting her blood. They seemed to signify the destructive and consuming nature of AIDS. Sarah experienced a loss of control. Sarah also imaginatively perceived the virus as an octopus. This image reflected HIV as an oppressive, suffocating force which desired to kill. Sarah imaginatively perceived HIV as a male. The qualities she defined as masculine i.e., power, strength, control and domination, were attributed to HIV. Sarah visualised HIV as a large, overpowering man cloaked in black. He assumed a ridiculing, taunting and antagonising stance, asserting his control over her.

Sarah experienced an acute sense of urgency and anxiety, and was absorbed by a preoccupation with time. For Sarah, the present was equated with a variety of tasks which still needed to be completed. The future however, appeared inaccessible to her. An inaccessible future implied a sense of meaninglessness. Sarah imagined her heart as a clock, and her urgent and pronounced heartbeat signified the embodiment of her preoccupation with time and death.

Sarah experienced immense discrimination and rejection. Her community and family's ignorance and fear of contamination regarding HIV, left Sarah spurned and humiliated. Sarah's community conceptualised HIV as a disease afflicting sexually deviant individuals. Individuals were judged and found guilty of transgressing a moral code. Labelled as a sexual deviant, Sarah was degraded and ostracised.

The hypocrisy and discrimination inherent in Sarah's community, inspired in her feelings of hurt and anger and in turn motivated her to punish those who had humiliated her. Sarah decided to expose her story to the media. Her decision to go public constituted a challenge and an assertion of her right to be acknowledged - an assertion of her existence amidst a climate of rejection and ostracism.

When Sarah went public she encountered empathy and support and was able to perceive her similarity to others. Sarah believed the process of sharing helped to alleviate much of the loneliness, stress and depression she felt. She felt motivated to work towards making others accept HIV- infected individuals.

To defend herself against the hurt she experienced, and to ensure her survival amidst a climate of discrimination and rejection, Sarah described herself as having a "heart of stone". She attained this state by cultivating an emotional indifference. Sarah likened the process of cultivating an emotional indifference to constructing a concrete wall. Sarah's wall served to demarcate a boundary between herself and the outside world which protected and distanced her from others. Others were prohibited from entering Sarah's world as she perceived her body as a private place.

Today, Sarah avoids intimate relationships because they constitute a potential invasion and threat to her private world. They are viewed as a disruption to her present educative intentions. Falling in love implies a dissipation of strength, potentially rendering one vulnerable and defenceless. Sarah refuses to surrender to the threat of invasion. Having a heart of stone preserves Sarah's strength and emotional indifference. This appears vital in order to ensure survival.

In order to live positively with HIV, Sarah assumes a specific attitude towards her virus. Firstly, an anonymous other prescribes to Sarah a potentially effective means of living with HIV. This entails establishing a relationship with HIV based on love and acceptance. Sarah appropriates this attitude of love and acceptance towards HIV. Sarah believes that relating to HIV as an enemy results in stress. Sarah's relationship with HIV is characterised by love in which she fully appropriates HIV as her own. Sarah's relationship with HIV is based on a shared investment in their mutual need to survive. After harbouring a desire to escape her body, Sarah now feels she inhabits her body in a comfortable fashion. Sarah feels that a harmonious relationship with her body will ensure survival.

Sarah believes that effectively controlling HIV entails possessing a strong and positive mental attitude. Sarah must make a decisive and sustained effort to maintain control over HIV, which means employing a specific mental procedure: When Sarah yields to her illness she begins to feel anxious and is preoccupied with death. This diminishes her strength and leads to stress. Sarah challenges herself to think positively and avoids relinquishing her control over HIV. When she feels ill, Sarah imagines HIV is deliberately deceiving her. HIV is depicted as a deceitful, unpredictable and manipulative trickster. Sarah responds by fighting and refuses to give in to her illness.

Sarah defines her present role as both educator and fighter. Sarah is motivated to educate others about HIV/AIDS in order to counteract the discrimination and ignorance which marks the disease. Sarah deems education as imperative because the severity of the AIDS pandemic is

intensifying. She feels challenged when people discriminate against her because it provides an opportunity to educate them. Sarah feels the government places more emphasis on education and prevention strategies than attending to those who are ill. Sarah believes those with HIV must be listened to and heard.

Sarah perceives herself as fighting two forces; the discrimination surrounding HIV/AIDS and HIV itself. Sarah's motivation for fighting the discrimination surrounding AIDS is inspired by previous AIDS sufferers. She feels she cannot relinquish her role as fighter and educator until she finds a significant female who will continue with her educative intentions. Women make an important contribution to AIDS work because they attend to matters such as women's rights and abandoned HIV-infected children.

Sarah feels she has a deeper awareness of, and appreciation for life. An acknowledgement of finitude implies a heightened dedication to the present. Sarah prefers to focus on the present rather than preoccupying herself with the future. This translates into a decisive dedication to living one day at a time. Sarah feels that she is more aware of things around her. Things that were once barely noticeable now seem to appear beautiful. Sarah displays an attitude of benevolence and responsiveness to others. She feels she is far more concerned for others and especially helps and accommodates people living with HIV.

4.2.2 Case Synopsis for Diane

Diane is a white female, 33 years of age and was diagnosed HIV positive six years ago. Diane divorced her husband after she discovered he was unfaithful and was molesting her daughter. She later found out that he had AIDS. Diane is now re-married.

Prior to being diagnosed with HIV, Diane had appropriated a picture/image of AIDS from a song - "Good girls go to Heaven, bad girls go everywhere". The title introduces a play of polarity - innocence, guilt, virtue and promiscuity. Diane defined HIV as a disease affecting sexually and morally deviant individuals, the antithesis of how she perceived herself. Diane believed she

would not contract AIDS because she was of virtuous, obedient and morally sound character. The medical profession perpetuated Diane's imaginative perception of HIV/AIDS by sharing and supporting her notion that individuals of good moral standing and virtue would not contract AIDS.

After giving blood out of duty rather than necessity, Diane was visited by the blood bank in the privacy of her home. Upon informing Diane of her results, the blood bank imparted a tactless and fatalistic message. Diane was explicitly informed she had AIDS, which would bring with it certain death.

Because she felt death would be instantaneous, Diane made practical preparations for her death. Diane embodied the metaphor of immediate death by figuring her body as a corpse and waited to die. After an initial feeling of numbness, Diane experienced a variety of feelings including denial, depression, disbelief, guilt and anger. Diane denied that she had HIV after the blood bank's prediction of immediate death failed to materialise. Requiring certainty of her diagnosis, Diane finally obtained another blood test.

Diane felt angry at both herself and her husband from whom she'd contracted HIV. Her feelings of anger and contempt toward her husband motivated her desire to punish him. She wished to murder him and did not fear the consequences of imprisonment. Diane felt that this would prove a satisfying endeavour. Diane felt a deep hatred toward all men and imagined that they were the carriers of HIV.

After receiving confirmation of her diagnosis, Diane sought support and visited the Catholic Church. They perceived Diane as a sinner for divorcing her husband and proceeded to reject her because of HIV. Diane was absorbed by feelings of guilt, betrayal, sin and isolation, and her perception of herself changed to that of a bad girl. Diane believed HIV was her punishment from God for divorcing her husband. Feeling like a condemned woman, Diane felt utterly rejected and abandoned by God. She proceeded to bargain with God in the hope that he might remove the

virus. She was desperate that God divest her of her punishment.

Diane experienced rejection from her parents. They treated her like an outcast and she felt humiliated and ostracised. Diane felt immense anger and responded to her parent's rejection by ignoring them. Diane's first experience of familial rejection influenced her subsequent perception of others. She imagined the entire community rejecting her. She labelled her community as condemners and judges of sin, and responded to others in a paranoid and suspicious manner. In effect, Diane withdrew and stayed at home. Diane's experience of HIV was lived as an isolated existence in which she felt vulnerable and fearful of exposure. At home Diane felt safe and invisible - protected from hurt, humiliation and rejection. Outside she felt exposed, vulnerable and defenceless. In hindsight, Diane recognises this was her imaginative perception.

Believing the virus was a punishment affected the way in which Diane inhabited her body. Diane's body felt contaminated and impure. In order to purge herself of HIV she fervently tried to cleanse and disinfect her body. Diane's desire to purge herself of the virus manifested in a suicide attempt as well as a deliberate and sustained effort at inflicting pain upon herself. Diane deliberately cultivated an unattractive appearance in the hope of remaining inconspicuous. Vulnerable, and fearful of exposure, Diane wished to distance herself from others. Fearful and ashamed of exposing her illness to others, Diane attempted to hide her physical manifestations of HIV. She felt that HIV was a secret which burdened her.

A significant religious encounter ultimately provided an opportunity for Diane to alter her present mode of existence. Diane chose to invest her faith in God and trust in Him wholeheartedly.

Before her religious experience occurred, Diane felt angry and disillusioned with God and possessed no faith in Him. God then miraculously appeared to her and informed her that she would publicly address her community about HIV. Despite feeling fearful and guilty for betraying her husband in going public, Diane felt compelled to carry out God's word. Diane

described God as a father figure who should be obeyed without question. Diane felt fearful and anxious before publicly imparting her story, yet she was responded to with warmth and affection.

Perceiving AIDS as Leprosy also marked a turning point in Diane's experience of HIV. When the Biblical story of God attending to the lepers was substituted with AIDS, Diane's perception of God changed. The image of a punishing and wrathful God was supplanted by a loving, tender and compassionate father figure. Diane felt accepted and her feelings of sin and guilt were allayed.

After a period of being angry with God, Diane now feels her relationship with Him to be her source of strength. When Diane feels sick she begins to feel a sense of urgency and anxiousness regarding time - particularly the future. Diane's relationship with God however, enables her to cope with HIV. Through Him, she has accepted and made peace with death and she feels secure in God's care and love. Working on nourishing her relationship with God, Diane explicitly refrains from actively communicating with her virus. Diane feels that her temperament does not predispose her to actively engaging in dialogue with HIV. Active dialogue would materialise into an argument and a fight with HIV the victor. Diane neither imaginatively perceives of, nor communicates with the virus in any concrete way. When Diane spontaneously visualises HIV she imagines the virus as a small, greedy man who consumes everything. Diane imagines HIV as masculine because she contracted the virus from a male. Diane also believes HIV is akin to a long, thin worm consuming T-cells.

To maintain a positive and strong mental attitude, Diane avoids being overwhelmed by her virus. For Diane, it is important not to attribute every illness she gets to HIV. Diane is aware of the physical manifestations of her virus, yet she does not dwell on them. Upon visiting a support group Diane felt more like a diseased object than a human being. She encountered negativity and felt distressed, unsupported and dehumanised. Despite this experience, Diane has been introduced to a number of AIDS and HIV sufferers who have supported her. She has encountered a unique and common understanding amongst other HIV sufferers because they had been through the same

experience. This has proved to be an immense source of strength for Diane.

Diane has experienced a host of both positive and negative emotions whilst living with HIV. At present, Diane does not believe HIV is a punishment from God. She appropriates HIV as a positive part of herself. Diane feels that experiencing HIV has made her more attentive and responsive to others. For Diane, HIV has provided an opportunity to fulfill her dream of teaching others. She is imbued with a sense of direction and meaning in life. Diane feels an enhanced sense of living fully in the immediate present and perceives the future in a positive and meaningful light.

Diane perceives herself as both educator and fighter and finds this role personally fulfilling and rewarding. Diane feels motivated to educate others about HIV/AIDS in order to alleviate the stigma marking the disease. Diane feels that statistics are meaningless because they conceal the humanity of each person suffering from HIV/AIDS.

4.2.3 Case Synopsis for Pat

Pat is a black male, 34 years of age and was diagnosed with HIV in 1996. Pat is currently very active with the National Association for People Living with AIDS (NAPWA).

Pat formulated an understanding of HIV as well as a vivid picture/image of AIDS prior to being diagnosed with the virus. His understanding of the origin of the virus was appropriated from political discourse. This discourse propagated a mythical and mysterious understanding of the disease in which the virus was attributed to devious, American scientific endeavour. Pat's picture/image of AIDS reflected the physical wasting and mental suffering accompanying the disease.

Pat was prepared for his diagnosis in a private setting where he was made to feel at ease. The doctor informed Pat that he had HIV and assured him that he still had a future. Whilst inquiring

about possible aid, Pat concealed his feelings of depression. The doctor was honest with Pat and explained the appropriate procedure for receiving aid.

At the time of his diagnosis, Pat had a variety of girlfriends. He was also unsuspectingly engaged in a relationship with a prostitute. After obtaining his diagnosis, Pat acknowledged that he contracted HIV from the prostitute with whom he had been living. Overwhelmed with contempt and anger, Pat devised a plan to murder his prostitute girlfriend.

At the time of his diagnosis, Pat failed to distinguish between HIV and AIDS. Pat believed his death would be instantaneous and could thus not imagine a future as an HIV positive person. He equated HIV with AIDS and AIDS with a very vivid picture of people dying. Pat imagined the physical and mental suffering accompanying AIDS and decided he could not subject himself to such suffering. Pat decided to commit suicide. However, after an unsuccessful suicide attempt which he attributed to Divine intervention, Pat was placed in a psychiatric ward.

In the psychiatric ward, Pat fantasised about becoming a serial killer. Pat imagined the virus as a judgement and a death sentence, inflicted upon him by a woman. He felt that HIV could not be considered a homosexual disease because he was not of homosexual orientation, nor had he ever participated in homosexual activities. Pat's perception of women - as weak and susceptible to the Devil's temptations - led him to believe that the devil had given women AIDS, that they were the carriers of the disease. Pat felt absorbed by feelings of anger and hatred. His anger manifested in a murderous desire to punish all women. Pat fantasised about either infecting them or violently beheading or axing all women to death.

Because his condition was still somewhat unstable, it was advised that Pat enter into the social environment of the Ark after hospital. At the Ark Christian Centre, Pat felt welcomed and accepted. He proceeded to educate himself about HIV and AIDS and was introduced to a variety of people suffering from HIV/AIDS. Pat encountered comfort, empathy and support upon meeting others with HIV and AIDS. He felt that others understood him.

To avoid directly confronting intimate others, Pat decided to publicise his story through the media. Pat described his community's understanding of HIV and AIDS as being characterised by disbelief and ignorance. HIV/AIDS was conceptualised as a disease emanating from, and affecting Western society. His community failed to distinguish between HIV and AIDS and could not relate the disease to real people. HIV/AIDS was also preserved as a secret. In Pat's experience, HIV was perceived of as an excuse for not wanting to engage in relationships.

At the Ark, Pat became preoccupied with the physical symptoms of his illness. These physical symptoms were aggravated every time Pat conjured up his image of the physical disfigurement accompanying AIDS. Pat felt that the physical wasting accompanying AIDS made it look as if a human being was being consumed by a greedy vampire. He thus imaginatively perceived HIV as a diabolical force - personified as a demon. Pat felt that the demon was relentless in its desire to consume human flesh. It was at this time that Pat also imaginatively perceived, and experienced HIV as a demonic ant inhabiting his body - an image which tormented him. Plagued with this image, Pat felt as if he was being consumed by the virus. Pat experienced a loss of control. He encountered difficulty sleeping, lost a considerable amount of weight and felt he was near death.

Contemplating the stories related to him about AIDS, Pat felt disillusioned. Influenced by the spiritual atmosphere at the Ark, Pat decided to invest his faith in God. Pat felt so tormented by the physical sensations of HIV, that he decided Satan was responsible for creating HIV in the form of a demon. Pat imaginatively perceived HIV as a torture and death sentence. He felt that HIV brought with it certainty of death but uncertainty regarding the exact time of death. To Pat HIV was synonymous with punishment - something which Pat believed God was not capable of inflicting upon human beings. He proceeded to identify HIV as the Devil's deadly game. Pat invested his faith in God's power to protect him from the Devil's destructive intent and chose to forget that HIV inhabited his body. In effect, a firm polarity between good and evil was created.

Pat's physical condition began to improve after establishing and nourishing a relationship with

God. Based upon Biblical scripture, Pat perceived God as the ultimate saviour, capable of performing miracles in his body. Pat appealed to God to remove HIV - the demon from the Devil - from his body. He anticipated that HIV would eventually be removed from his body. This belief was strengthened through active communication with God.

Pat's belief in God provides him with an effective means of dealing with HIV. Pat believes that he and God participate in a mutual endeavour to conquer HIV's existence. Pat's body is akin to a landscape within which the fight between good and evil takes place. Pat feels that this imaginative perception helps him to maintain his strength. He prays to God and his ancestors for guidance and strength. Pat believes his body is God's temple and he describes himself as embracing and bodying forth a free and open attitude to the world.

Pat also controls HIV by avoiding anger because anger inspires anxiety. Pat cares for his body and possesses a positive mental attitude. He no longer indulges in alcohol. Unable to afford an effective treatment for HIV, Pat invests his faith in God and follows the doctor's advice. Pat lives according to the will of God.

Through his involvement with HIV/AIDS work, Pat has been introduced to many people and received direction in his life. Pat feels motivated to educate others and fight the stigma attached to HIV/AIDS. Having HIV has provided Pat with the opportunity to do so.

4.3 David's dialogue with HIV

As was mentioned in Chapter Three, a tape recording of one participant's (David) dialogue with HIV was obtained and transcribed. The researcher felt this to be an important source of additional data. The data transcribed from the tape recording is presented below.

David was diagnosed with AIDS in 1983. He was 22 years of age. The doctor diagnosed him with AIDS and said that he had one year to live. Today David is 36, still HIV positive and one

of the world's longest surviving AIDS patients.

When experimenting with different therapeutic techniques, David found many visualisation exercises ineffectual. He felt that these exercises encouraged people to fight their virus. People were left with the feeling that they had lost, "a had to win" frame of mind existed. David felt that if he had to win, whatever he was challenging had to lose, where there is a winner there's a loser. David was uncomfortable with the notion of winners and losers. He decided to try a different way of thinking. Based upon his intuition of the HIV virus, David felt sure that it had the same instinct to survive that he had. The same force that directed him to fight for his life motivated the virus. If he challenged the virus's survival instincts it would raise its defences and mobilise against him. David felt that the challenger, and a state of war would exist between them. David had seen many friends take on the virus, and for a period of time they would be victors. But at some point their fight against the virus would turn direction and the virus would appear to be getting the upper hand. Most of these people died.

David decided to follow his instincts and literally embraced his virus for what it was, a living organism that dwelled in his body. He wanted a truce or a cease fire to be declared so that they could both live in his body, co-existing in a non-threatening state with one another. No winner, no loser. This meant that there was no reason for either of them to try and destroy the other. If neither of them felt challenged, then a state of harmony could exist and would exist between them. This went against everything David believed and read about HIV. Before speaking to his virus David had to come up with a set of guidelines or rules, as one would ordinarily do when negotiating some kind of cease-fire agreement. This included terms and conditions acceptable to both of them. David had to understand his needs as well as the needs of the virus. He decided upon the following: Firstly, he recognised each of their instincts to survive at all costs. He then recognised that they both had the right to survive, and finally acknowledged that they could both co-exist in his body

David then put himself in the virus's "shoes" and tried to understand the needs of the virus - to

survive was the only motivator that he could identify. He didn't feel the virus was motivated to destroy him because if it killed him, it would kill itself and they would both lose, they would both be dead. If the virus's instinct was one of survival then it wouldn't want to die. This was the main bargaining tool that David brought to the negotiating table. He also realised that like human beings, the virus had an instinct to pro-create, to continue its line. This meant that in order to pro-create it would need other bodies to infect. This scared David. He decided that he could not and would not allow this virus to leave his body and infect another. He had to contain the virus within himself. He decided to enter into conscious dialogue with his virus. David invited the virus into his heart with love as the motivator.

The following is a direct account of David's dialogue with HIV:

"I acknowledge your right to exist. Like me, you are a living form whose primary instinct is to survive at all costs. I acknowledge and accept this as a truth. I understand and accept that you are powerful and that you have the ability to consume my body and destroy it thereby destroying me. I do not wish to fight you. I do not wish to destroy you. I wish you no harm. I do not wish for you to destroy me. I do not wish you to fight me. I ask you to acknowledge my right to survive. I ask you to acknowledge that I have power against you that could destroy you. I ask you to acknowledge that if I choose to, I could destroy you simply by destroying myself. I ask you to acknowledge that if you destroy me neither of us will exist any more. I ask you to acknowledge that I therefore, have as much power against you as you have against me. I ask you to acknowledge that we are both powerful. I would like to ask you to enter into an agreement where we could both live and exist in my body. And by living in my body neither of us will have to be the victim. I would like to ask you to co-exist with me. This co-existence can only take place as long as neither of us has the desire to win. I am not willing to challenge you or your right to exist any more. I ask that you not challenge me and my right to exist any more. I ask you to acknowledge that if I die because of something you do, that you too will die because without life in my body you cease to exist. I ask that we live together in peace and harmony and that we create a relationship based on mutual respect for our individual rights to live and exist. I ask that you agree never to leave my body and enter into that of another person and please know that I will do everything in my power to ensure that you stay within me. I ask that you commit to and respect this truce state that exists between you and I. I ask that you respect the power I have over you, and I will respect the power that you have over me. I will not challenge your power on the condition that you not challenge mine."

4.4 Extended Description

A synthesis of the themes gleaned from all participants is presented below¹. This is an essential, integrated, meaningful structure of the experience of HIV.

Participants' understanding of HIV is profoundly shaped by the specific socio-cultural context from which they emanate, and the particular situation in which they find themselves. Their understanding of HIV is superseded by social, metaphorical understandings of the disease as being equated with AIDS and immediate death, synonymous with sexually deviant behaviour or regarded as a myth. Participants (S,D,P) appropriate a particular image/picture of HIV/AIDS prior to their diagnosis which is derived from these metaphorical understandings of HIV/AIDS. In most cases, the fantasy of HIV/AIDS establishes its reality and acts as a leitmotif throughout participants' lived experience.

Upon being diagnosed, participants are confronted with the reality of immediate death. The fantasy of HIV as being synonymous with immediate death and AIDS is shaped and affirmed by some medical practitioners. Participants (S, D) are imparted a fatalistic and tactless message regarding the disease, and all participants fail to differentiate between AIDS and HIV irrespective of the manner in which they are informed of their diagnosis. HIV is initially lived as an isolated existence in which participants are absorbed, at one time or other, by feelings of fear, anxiety, confusion, uncertainty and meaninglessness. Participants feel an acute sense of fear regarding the physical suffering that AIDS (and therefore HIV) exemplifies, and a distinct feeling of anxiety and urgency related to the issue of time (S, D, P, J, M).

Fear of physical suffering leads some participants to regard HIV as a death sentence, torture and punishment (S, D, P, J). For some participants suicide is a preferable option to the physical suffering that AIDS implies (D, P). HIV is imagined as a powerful and destructive force that torments and consumes the physical body (S, P). Perceiving HIV in this manner impairs

¹ Letters represent the participants whose experience substantiates the text. For example; S=Sarah, D=Diane, P=Pat, J=Jan, M=Mercy and Da=David.

participants' capacity to inhabit their bodies in a comfortable manner. Feelings of anxiety regarding death induce a sense of urgency, and constitute a failure to live authentically in time. The present is equated with a variety of tasks which still need to be completed, yet the future appears inaccessible. Participants' preoccupation with time and fear of death are experienced in a number of embodied metaphors (S, D, P).

Participants' primary attunement to the world is also reflected in feelings of anger, injustice, and betrayal. HIV, with its certain death is perceived as an unjust affliction. Feelings of anger and blame are directed at God or the individual responsible for transmitting the virus. In some instances, feelings of anger manifest in a premeditated plan to murder accused partners (D, P). Feelings of anger are generally extended towards all members of the guilty sex (D, P, M). Although other people are blamed for transmitting the virus, some participants acknowledge and accept responsibility for contracting HIV (D, P).

Participants are confronted with a particular social, metaphorical understanding of what it means to be an HIV- infected person; HIV/AIDS is synonymous with sexually deviant behaviour. Individuals with HIV are judged and found guilty of transgressing a shared, moral code. The Church, medical profession and society at large appear to share and support this notion that individuals of good moral standing and virtue will not contract HIV. A play of guilt, innocence, promiscuity and virtue is set up. HIV is perceived by some as a punishment (D, J) for past transgressions. Participants experience familial rejection which influences their subsequent perception of others. HIV is thus lived within a context of accusatory others in which participants feel akin to sinners and outcasts - guilty and alienated (S, D, J, M). Attuned to this identity as outcast, and absorbed by feelings of hurt, individuals retreat from the open world-disclosure they inhabited prior to their HIV existence (S, D). HIV is lived as an isolated existence in which participants feel fearful of exposure and vulnerable.

For some participants, HIV/AIDS is regarded as a myth in their respective communities (P, M). AIDS is conceptualised as a disease emanating from, and affecting, Western society. This has

implications for interpersonal relationships; participants find it difficult to convince others that they are HIV-infected because HIV is perceived as an excuse for avoiding sexual contact.

An opportunity ultimately presents itself for participants to publicly divulge to others their HIV status. Public revelation is unanimously declared a necessary and cathartic step in being able to cope effectively with the virus. Participants are introduced to other people suffering from HIV/AIDS and encounter empathy, compassion, comfort and support. Participants are able to perceive their similarity to others which counteracts feelings of isolation. Participants proceed to assume the identity of fighter/warrior, teacher/educator and mentor. All participants find themselves in educative roles, or roles which prove personally meaningful and fulfilling. They consider eradicating the discrimination, stigma and ignorance associated with HIV/AIDS, as a challenge and a cause worth fighting for.

In order to live with HIV, most participants, consciously establish some form of relationship with the virus or with a Higher Power. Participants (S, M, Da) seem to foster a direct relationship with HIV in order to coexist with it. This relationship with HIV is based on a shared investment in their mutual need to survive. Effectively living with the virus entails adopting an attitude of love and acceptance towards HIV. Perceiving HIV as the enemy, a force which must be fought against, is an attitude explicitly avoided (S, M, Da). Alternatively, and in the case of one participant, HIV is imaginatively perceived of, and related to, as a diabolical force which must be conquered with the help of God (P). This is deemed an effective manner of dealing with the virus.

Some participants fervently refrain from establishing a relationship with their virus (D, J). Instead, establishing and nourishing a relationship with a Higher Power is deemed the only effective means of living with HIV. A strong spiritual theme runs through some participants experience of HIV (D, P, J). A point is reached where participants choose to perceive God as a loving and compassionate father in Whom they invest their faith.

For most participants the encounter with death and isolation leads them into a more authentic mode of existence. HIV is affirmed and appropriated as one's own. Temporality (lived time) is marked by a shift from a preoccupation with the future to a dedication to the present (S, D, P, J, M). An acknowledgment of finitude lends a heightened sense of meaning and significance to the present and the pleasures that currently exist. Participants display an attitude of responsiveness and benevolence towards others.

4.5 General Structure

In the experience of living with HIV, individuals are confronted with a socially and institutionally prescribed understanding of the disease; HIV is synonymous with AIDS, immediate death and sexually deviant behaviour, or regarded as myth. Lived within a context of real or imaginary accusatory others, HIV is subsequently internalised as a death sentence, torture and punishment. HIV is imagined as a consuming force which torments the physical body. This is evident in a number of evocative images. Some individuals' experience of HIV is characterised by the embodiment of specific metaphors, eg., embodying a heart of stone to live with HIV, embodying HIV as punishment, or embodying HIV as demon from the Devil. These metaphors yield a decisive impact upon the way in which individuals embody their world. Affectively, the experience of HIV is constituted as a variety of negative feelings including, fear of physical disfigurement and fear of exposure, anxiety, vulnerability, anger, betrayal, injustice and isolation. Attuned to these possibilities, individuals retreat from the open-world disclosure that constituted their pre - HIV existence and their capacity to authentically relate to their body, others and time is impaired. In the experience of HIV, an opportunity ultimately arises in which individuals publicly reveal their situation to others and assume the identity of educator, fighter and mentor. HIV is appropriated and affirmed as one's own and individuals are able to return to being fully present in their openness to the world and time. Establishing and maintaining effective coping skills to deal with HIV, are achieved by establishing a metaphorical space in which to dwell with the virus. This is attained through direct negotiation with HIV or a Higher Power.

The following tables summarise the salient metaphors and images that emerged from the data. The letters in brackets represent participant one, two ...etc. These metaphors and images will be discussed in greater detail in the following chapter.

Table 1: A summary of the social metaphorical understandings of HIV/AIDS which participants come to internalise.

1. HIV/AIDS as immediate death (S, D, P, J, M)	Leads to feelings of fear and anxiety with regard to an impending physically abhorrent death, as well as feelings of anxiety and urgency related to the issue of time.
2. HIV/AIDS as secret (S, D, P, J, M)	The lack of openness and secrecy surrounding AIDS inhibits participants' capacity to relate to their world in an open and receptive manner. Inspires feelings of alienation.
3. HIV/AIDS as sexually transmitted disease (S, D, P, J)	Leads to feelings of humiliation, shame, guilt, sin which inspires anger and isolation
4. HIV/AIDS as myth (P, M)	Failure to seriously acknowledge AIDS as a disease contributes to fear and ignorance as well as making it difficult to be open and share the experience with others
5. HIV/AIDS as punishment (D, P, J)	Implies that participants have behaved in a deviant way which leads to feelings of guilt, sin and isolation.
6. HIV/AIDS as death sentence (D, P)	Again supposed deviant behaviour has resulted in participants being sentenced or judged for their wrong doings. Inspires feelings of anger, anxiety, meaninglessness and isolation.

7. HIV/AIDS as judgement (D, P)	Very much the same as 5 & 6. To be judged implies one has done something bad which must be punished. Leads to feelings of guilt, sin and alienation.
8. HIV/AIDS as torture (S, P)	Implies participants are being persecuted by the enemy. Sets up roles such as victim (HIV infected) and persecutor (AIDS/HIV or discriminatory others). Engenders a conflict which is responded to by fighting.

Table 2: Metaphors that serve to inspire a positive shift in identity.

1. HIV/AIDS as leprosy (D, J)	Because God accepted lepers, he too will accept those suffering from HIV and AIDS. This counteracts feelings of isolation, of being an outcast and a sinner.
2. HIV/AIDS as challenge (S, D, P, J, M)	Perceiving the stigma surrounding HIV/AIDS as a challenge worth fighting against gives participants a new lease on life. Their identity shifts from outcast and sinner, to educator, mentor & fighter.

Table 3: HIV personified: As a personified image, HIV comes in many forms and guises.

1. <i>HIV as male</i>	According to Sarah, HIV is a male. He adheres to Sarah's image of males; demanding, dominating & overpowering. Personified, HIV is a huge (7foot) man. He is dressed in black and assumes a ridiculing and antagonising stance. Diane imagines HIV as a male because it was a man that gave her the virus. Personified, he is like a little pac-man or jelly tot man gobbling up everything.
2. <i>HIV as creature</i>	For Sarah, HIV is akin to an octopus which clings and doesn't let go. HIV is likened to and subjectively experienced as devouring ants by both Pat and Sarah. Pat feels these ants to be demonic. He further describes them as bisexual because they choose to inhabit the bodies of both men and women. Diane refers to HIV as a long, thin worm consuming T-cells. These images suggest that HIV is greedy and ravaging. It lives to devour the life within.
3. <i>HIV as enemy</i>	Pat describes HIV as a crazy monster in the form of Dracula, slowly draining the life of a human being. This personified image correlates with his understanding of HIV as a demon from the Devil.

4. <i>HIV as special</i>	Jan believes that if he had been infected with HIV in a loving sexual act, the virus could then be considered special. Mercy refers to HIV as a special and unique virus because it desires to dwell in a human body. Furthermore, it makes its entry through two of the most special paths, that of intercourse and blood.
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CHAPTER FIVE

DISCUSSION AND CONCLUSION

The aim of this study was to understand what it means to live with HIV by exploring the metaphors that mediate such an experience. The findings of this study were presented in the previous chapter. In the following chapter, the implications of the central themes and metaphors emerging from participants' experience are addressed. These implications are largely discussed in terms of the significance they have on the way in which participants come to embody their world. Where relevant, direct excerpts from participants' experience will be used to illustrate points of discussion.¹ This is deemed appropriate since imaginative accounts of experience often lose their immediate potency when translated into the third person.

Using the Extended Description as a point of reference, the findings of this study are dialogued with the literature reviewed in Chapter Two. The discussion consists of four main sections: Firstly, a discussion of the main socio-cultural metaphors informing participants' understanding and experience of HIV. Secondly, a discussion of positive metaphors imbibed by participants and the possibility of transformation in the experience of HIV. Thirdly, a discussion of ways in which participants come to effectively cope with HIV. Finally an evaluation of the approach assumed in this research is included as well as suggestions for further research and concluding comments.

5.1 Discussion of social metaphors - the potency and influence of the "they"

By situating participants' experience of HIV in a broader socio-cultural context and describing how their experience of HIV unfolded, a number of salient points were revealed. What emerged strongly from the data was the potent influence of society's pre-conceived fantasies of what it meant to have HIV/AIDS. Hillman (1977) writes that fantasy presupposes all reality and it is through fantasy-images that we create our worlds and come to call them our realities. For each

¹ Reference to participants' extracts or examples are numbered according to delineated NMU's and can mainly be accessed in appendices.

participant, the fantasy of HIV/AIDS established its reality.

By locating aspects of individuals' experience in Heidegger's conceptual analysis of *Dasein* and inauthentic and authentic being, we begin to see how having HIV confronts individuals with a choice. Individuals have to decide how they are going to live with HIV. Departing from a collective understanding of HIV/AIDS implies coming to live with HIV from one's own standpoint rather than what is interpreted in the eyes of the other. In other words, an encounter with HIV provides the potential for a shift from inauthenticity to a more authentic mode of existence.

Analysing human existence at the level of everyday life, Heidegger (1962) determines that for the most part, *Dasein* is characterised by inauthenticity, a mode of being in which *Dasein* gives itself over to the already interpreted world of the "they" - *das-man*. To exist is to be caught up in the world as interpreted by others. Existing in this way, man/woman immerses him/herself in the preconceptions and diversions of what is interpreted by the anonymous "they", and is thus relieved of the burden of choosing the possibilities and potentialities of his/her own being. Heidegger identifies idle chatter as being a constituent mode of *Dasein's* openness to inauthenticity. Exploring the fantasies which informed participants' understanding of HIV/AIDS in light of Heidegger's conceptual framework illustrates the omnipotence and potent influence of *das-man*.

When participants were asked how they pictured or imagined HIV/AIDS prior to being diagnosed, it became clear that the meaning of HIV/AIDS had been constructed from the already interpreted world of *das-man*. An understanding of HIV/AIDS was conveyed and controlled through the already interpreted idle-chatter of the "they". Recall Sarah's fantasy of AIDS which she derived from a media advertisement (S9). Several aspects of Sarah's experience also indicated that anonymous others were constantly propagating a prescribed meaning of HIV/AIDS. For instance, Sarah (S11) stated, "I was scared to sleep at night because AIDS kills *they* said...." Upon describing her experience of ants infesting her body Sarah remarked (S14),

“I thought that this is what the virus should look like because *they* say it is destroying me from the inside ...”

Diane appropriated her fantasy of HIV/AIDS from a popular song; “Good girls go to Heaven, bad girls go everywhere”. For Diane, HIV affected “bad girls” and this imaginative perception was affirmed by the medical profession (D9,12). Pat’s fantasy of HIV was appropriated from political discourse (P22) which propagated a mythical understanding of the disease. Participants were delivered over to these fantasies which continued to persist and manifest in the way they were called forth to deal with their diagnosis. Heidegger (1962) writes that ‘the “they” prescribes one’s state-of-mind, and determines what and how one “sees”’ (p.213). The fantasies of *das-man* influenced how participants responded to and perceived HIV/AIDS. The potency of such fantasies translated into various thematic images and metaphors which characterised participants’ experience.

The fantasies of *das-man* were reflected in three major metaphors, namely; HIV as AIDS and immediate death, HIV and AIDS as sexual deviance, and HIV and AIDS as myth. These metaphors introduced further metaphors, for example; HIV/AIDS as secret, HIV/AIDS as judgement/punishment and HIV/AIDS as death sentence/torture (Table 1, p.111-112). Metaphors such as these are typical examples of what Sontag (1989) would refer to as stigmatic and pejorative fantasies. They carry with them connotations of moral weakness and transgression, contamination and dehumanisation - all the qualities which motivate Sontag to decry the excess of “lurid” fantasy in illness.

Considering the aim of this research, understanding the depth of meaning and impact that these various metaphors yielded for participants was of fundamental concern. Understanding the meaning of these metaphors in a psychologically relevant manner entails working from Hillman’s (1977) standpoint on illness and fantasy, rather than from Sontag’s orientation towards depriving illness of meaning. As Hillman (1977) claims, ‘the fantasies of sickness are assumed from the outset and in entirety to be part of psyche’s depth’ (p.84). It is therefore

important to follow these fantasies and images that inform participants' experience without hastening towards an explanation. By observing and *describing* each participant's experience, it became evident that these social metaphors impacted upon the way participants were called forth to embody and live with their virus.

5.1.1 HIV as AIDS and immediate death

- *fear of disfigurement*
- *HIV as consuming entity*
- *failure to authentically inhabit body*
- *suicidal tendencies*
- *failure to live authentically in time*
- *fear of contagion*
- *denial*

Upon being diagnosed with HIV, participants were confronted with the fantasy of immediate death. The fantasy of HIV as being synonymous with AIDS and immediate death was actually supported and propagated by some practitioners who failed to distinguish between HIV and AIDS. Recall Van den Berg's (1972a) statement, that 'every patient suffers, apart from suffering from his disease as such, from the disease as it exists in the opinion of his physician' (p.85). Participants were called to deal with their diagnosis based on how HIV was regarded and conveyed to them. Instead of an explanation of the difference between AIDS and HIV, some individuals were simply told they had AIDS (S4; D4). Diane, for example, was told of her results in a fatalistic and tactless manner. Diane remarked, "... she said to me, "You've got AIDS, you're going to die, deal with it." Those were her words." Those participants who were told they had HIV still failed to distinguish between HIV and AIDS (P3; J42; M1). The significance of perceiving HIV as synonymous with AIDS and death was realised in how participants initially understood, related to and dealt with HIV.

D'Anzi (1987) and Jackson (1988) report that common responses to HIV- infection include confusion, fear and uncertainty. Yalom (1980) writes that an encounter with death may lead to confrontation with certain existential concerns including isolation and meaninglessness. As the results showed, HIV was initially lived as an isolated existence in which participants were

absorbed by feelings of fear, anxiety, confusion, uncertainty and meaninglessness. It was evident that the metaphor of immediate death compounded or heightened the usual feelings of fear, isolation, anxiety and meaninglessness that an encounter with death may engender.

Most participants felt an acute sense of fear and anguish regarding the physical suffering that AIDS, and therefore HIV, exemplified (S19; P11; J43,44; M7). HIV was equated with a swift and physically abhorrent death. Writers such as Lupton (1994) and Sontag (1989) maintain that social metaphors regarding the physical nature of AIDS produce fantasies that in a way sensationalise what it means to die with AIDS. Goffman (cit. in Brandt, 1985 and Goldin, 1994) refers to a stigma known as 'abominations of the body', whereby the physical disfigurement of disease is emphasised and therefore feared. As Sontag (1989) points out, AIDS is associated with various physical deformities, transforming the body into something alien and repulsive.

Some of the images described by participants clearly reflected their fear and anxiety, and evoked how HIV was construed. HIV was perceived as a threatening, greedy and destructive inhabitant that tormented and consumed the physical body. Sarah imagined and experienced HIV in her bloodstream as thousands of feasting ants destroying the life inside her (S14,15,51,52,53). Sarah also perceived HIV as an octopus - an oppressive, suffocating force which desired to kill her immediately (S67). When Pat pictured an HIV sufferer, the symptoms of AIDS began to torment him. He imagined and experienced HIV as a demonic ant slowly eating away at him (P26,42,43,47,48,58). He also imagined HIV as a diabolical force, greedily consuming the blood of a human being. Referring to HIV, Pat remarked (P50,59):

"I see the virus as evil. Something like a monster, or a Dracula, or a vampire, a real demon. Something which is always crazy for the blood of a human being. When a person has AIDS they get very thin, all skin and bone. When you look at that person they look as though the blood has been drained from them. A person who has been slowly, slowly drained by a blood thirsty vampire."

Diane spontaneously pictured HIV as a long, thin worm consuming T-cells (D44). It is

interesting to note that these participants' images of HIV clearly established the virus as a definite other.

Because participants' bodies in a sense contained a threatening virus intent on destruction, some individuals' capacity to authentically and fully inhabit their body was impaired. For instance, Sarah felt an initial desire to escape and disown her body (S7, 46, 49). She remarked (S46,49):

"If I could escape my body and leave it that day I would have. My body felt strange to me ... It was useless to me because it was full of HIV and not HIV for that matter remember the doctor said AIDS, it was full of AIDS ... I just wanted to get rid of it. Like an old pair of shoes - you don't see the need of wearing them any more - you just get yourself a new pair and leave this pair behind."

In a sense Sarah's body implied limitation to her, it had no function any more. This sense of detachment implied alienation. As Jager (1984) writes, 'alienation, painful discordant embodiment, is itself a loss of access to the flesh of nature ...' resulting in a failure 'to fully inhabit one's world' (p.55). Because Sarah's body felt alien to her, her access to the world was impaired. Her feelings of discomfort in her body and her fear of death signified a loss of access to the world. At night she awoke sweating and rushed to the window to check that she was still embodied on the earth (S11,12,48). She described "tomorrow" as "dark, down there". Sarah's experience authenticates Heidegger's (1962) notion of uncanniness (not-at-homeness), 'a state in which one loses one's sense of familiarity with the world' (Yalom,p.359), and encounters a sense of isolation and nothingness.

Believing that HIV inspired an immediate and tortured death, Pat and Diane for example, displayed a preference for suicide rather than experience the suffering AIDS engendered. To them, HIV was a death sentence. For example, Diane (D60) remarked, "To me the virus was a death sentence. I was told it was - you're going to die they said." Pat remarked (P11):

“My idea about AIDS was a person gets thin and thin with sores around his mouth and face and body. I didn’t want to experience that. I also thought of other people with AIDS - it affects their brain. I just looked at that and I thought; I don’t want to suffer like that.”

Karasic & Dilley (1994) point out that the option of suicide may help the person with HIV have a sense of control, that he/she has some choice over the amount of suffering or disfigurement he/she will have to bear. This was evident in Pat and Diane’s case. D’Anzi (1987) remarks that individuals infected with HIV may feel a sense of helplessness which arises as a result of fear of the unknown and aloneness. Pat and Diane’s preference for suicide may be interpreted as a way of reclaiming control over their helpless situation.

Faced with the threat of immediate death, participants encountered a sense of anxiety, urgency and meaninglessness which was largely related to the issue of time. An encounter with the metaphor of immediate death thus introduced the theme of temporality. Encountering the threat of immediate death meant confronting the reality of finitude, and in relation to temporality, signified what Heidegger (1962) would refer to as ‘the impossibility of further possibility’. Temporality (lived time) was such that some participants could not envisage the future as holding meaning or possibility (S6,8,13; P7; J41). Much of this sense of meaninglessness was pre-empted and in some ways largely influenced by those who informed participants of their diagnosis. There was a failure to instil in some individuals hope that they might still live with HIV. For most participants, the present and future were only viewed in terms of the physical suffering that accompanied death. This metaphor heightened participants’ feelings of anxiety and isolation. We somehow grasp the intensity of the urgency and isolation some participants felt through the imagery they describe. The sense of urgency and meaninglessness they felt was imaginatively embodied.

Upon hearing that she had “AIDS”, Sarah’s brain began to work like a tape-recorder playing back and forth. She remarked (S6):

“I press the rewind button in my brain to work out where it happened, why it happened, why me?, and then I used the fast forward button to say, what am I going to do now?, where do I go to from here?, what do people with AIDS do?, people with AIDS die - I have no life.”

So too did Sarah imaginatively experience her heart as a clock denoting to her the time limit to her life (S16,50). After Diane heard she had AIDS she carefully prepared to die. She figured her body as a corpse in a coffin and awaited her death (D48). For most participants the future appeared inaccessible. Sarah described it as “cut off and dark”. Pat could not imagine a future as an HIV positive person because to him, AIDS was equated with suffering and a painful death (P7). He continually conjured up this physical picture of people dying from AIDS.

Much of the confusion, isolation and fear participants felt was exacerbated by the uncertainty surrounding the physical nature of HIV. This uncertainty was not only confined to participants’ understanding of HIV but related to the wider context in which they found themselves. Dunkel & Hatfield (1986), and Macks (1988) remark that fear of the unknown and fear of contagion are common responses to HIV-infected individuals. These fears were evident in Sarah’s environment where she was forbidden to be in physical proximity to her own children lest she contaminate them. Sarah was perceived by others as harbouring something threatening and indiscriminate. This meant that Sarah had to remove herself from others, diminishing her openness to the world.

One of the implications of the fantasy of immediate death, was that when some participants realised that death had not yet “visited”, they tended to feel ambivalent about their diagnosis. Kubler-Ross (1969) identifies *denial* as a stage in the process of coming to terms with one’s death. The stage of denial is characterised by an individual’s failure to acknowledge the severity of his/her disease and the inevitability of death. This was representative of Diane’s experience. Upon waking to find she was still alive, Diane felt she couldn’t have HIV (D6, 49). For a long time Diane denied the existence of the virus in her body.

5.1.2 HIV and AIDS as sexual deviance

- *punishment/judgement*
- *anger, injustice, betrayal, blame, bargaining*
- *humiliation, sin*
- *isolation*

Participants formulated a metaphorical understanding of what it meant to be an HIV- infected person through internalising society's pre-conceived conceptualisations of the disease. The Church, medical profession and society at large, appeared to share and support the notion that individuals of good moral standing and virtue would not contract HIV. For example, upon informing the medical profession (for whom she worked) that she had HIV, Diane recounted how they were quick to agree with her statement that "good girls" don't get AIDS (D12). Most participants felt they were judged and regarded by society as sexual deviants because they had HIV. The metaphor of HIV/AIDS as sexual deviance led some participants to construe the virus as evil - a punishment for deviant behaviour. For instance, Jan (15,40,46) remarked:

"The punishment - it's what society and the church tell you. One minute before diagnosis I was a normal person, part of the community, a happy man. The next minute I imagine myself to be a sinner, evil, going to contaminate my surroundings..."

According to Sontag (1989) considering illness as a punishment is one of the oldest ideas of what causes illness. Because HIV/AIDS is conceptualised as a sexually transmitted disease, it is considered to put those who are sexually more active at greater risk, and as Sontag (1989) points out, 'it is easy to view it as a punishment for that activity' (p.26). Furthermore, as a study conducted by Norton et. al. (1990) shows, most metaphors concerning HIV/AIDS as a judgement and a punishment, link the disease to an angry God. This was evident in the case of Diane and Jan who both believed God was punishing them by giving them HIV. It is interesting to note that Pat considered HIV to be a punishment from the Devil in no way related to God.

Participants expressed their response to these social metaphorical understandings in terms of feelings of anger, humiliation, guilt, injustice, blame, betrayal, alienation and sin, which

characterised their primary attunement to the world. Kubler-Ross (1969) identifies anger, bargaining and isolation as further stages in coming to terms with one's death. Jackson (1988) comments that anger, bargaining and guilt are typical emotions that characterise the "mourning process" HIV- infected individuals experience after hearing their diagnosis. It is emphasised again that in relation to HIV, feelings of anger, guilt and isolation were in a sense related to the social metaphors informing participants' experience.

Because HIV was socially considered to be transmitted through deviant sexual behaviour, some participants felt that they were 'innocent sufferers' (Norton et. al., p.821). HIV was perceived as a judgement and was therefore something inflicted upon them which they didn't really deserve (D59; P61). Conceiving HIV as some kind of unjust affliction, some participants felt angry and betrayed. Anger was tied up with blame and initially directed at God for abandoning them (S7; D53; J19). This anger manifested in a type of bargaining taking place, as Jackson (1988) describes, 'a plea to supernatural or human agents to take away the terrible news ... in return for a particular action or change in behaviour' (p.76). Both Diane and Sarah recounted how they bargained with God to take their virus away (S7; D7). Pat actively engaged in negotiation with God to remove HIV from his body in return for good deeds. In a sense their disbelief that they could have HIV made them believe that in some way God could take the virus away. Death was difficult to accept and own because in a sense someone else had passed judgement and was responsible for the fact that they were going to die.

Because HIV/AIDS was felt to be some kind of judgement, a polarity of innocence, guilt, promiscuity and virtue was set up which created a divide between individuals. This contributed to feelings of anger, hostility and alienation. The results showed that much of participants' anger was directed at those who had transmitted the virus. The intensity of this anger was evident in Diane and Pat's desire to commit murder (D8,58; P9) . Both participants wished to murder the person who infected them. Pat even harboured a fantasy of becoming a serial killer and infecting or murdering all women (P57,60). The desire to spread the virus is a common characteristic of anger identified by Jackson (1988). The metaphor of sexual deviance also induced feelings of guilt in some participants. This was sharply witnessed in Diane's experience whereby HIV was perceived as a punishment for past transgressions.

Feelings of isolation were common amongst participants. Isolation, in the encounter with HIV, was heightened by the stigma surrounding what it meant to be an HIV- infected person. Most participants experienced a long period of alienation due to the fear, ignorance, discrimination and rejection they encountered from their family or community. Others were perceived as hostile and disapproving and participants felt akin to sinners and outcasts. As Jan remarked (J16):

“...in my circle of friends and society, the concept is sexual. It is sexually transmitted with prostitutes... when I was diagnosed I didn’t want to say anything about it because of the sinful concept. I felt like a sinner.”

The lack of openness and secrecy that surrounded HIV/AIDS implied a disturbance in some participants’ capacity to relate to their world in an open and receptive manner. This was most evident in the case of Sarah and Diane. Their response to the rejection and alienation they encountered revealed itself in the conscious embodiment of specific metaphors.

It is useful to discuss the way in which metaphor affects Sarah and Diane’s experience of living with HIV, because it reveals much of the way in which illness comes to be embodied as a world. Van den Berg (1972a) asserts that the world is the dwelling place of illness. We can begin to grasp the significance of what Van den Berg means in light of Sarah and Diane’s experience. In both instances, these participants’ experience of HIV was characterised by an inability to body forth an open relationship to their world.

5.1.3 Illness - embodied as a world

- *HIV as punishment*
- *Heart of stone*

What both Diane and Sarah’s experience signifies is how potent metaphor is, and the ontological import it has. Both Hillman (1977) and Romanyshyn (1975, 1982) advocate that metaphor has ontological importance. When we say that metaphor is a *figure of speech*, we tend to regard it purely as an epistemological device, and the *figure* implicit in the linguistic metaphor remains opaque. To acknowledge the ontological dimension of metaphor is to see that metaphor is in fact

an embodied perspective. In other words, the body is inherently metaphorical by nature, an imaginative and meaningful subjectivity giving concrete expression to metaphor. This is clearly revealed in Diane's experience and to a degree in Sarah's. By saying "*HIV is a punishment*", or "*I had to have a heart of stone to survive living with HIV*", Diane and Sarah (respectively) are alluding to far more than a figure of speech. These metaphors reflect the way in which they came to constitute their world.

Rejected by the Church because she had HIV, Diane was absorbed by feelings of guilt, betrayal, sin and isolation and believed the virus to be a *punishment from God* for getting divorced. Diane perceived herself to be a sinner - an outcast - and she felt humiliated and abandoned. Diane perceived others as hostile and labelled her entire community as condemners and judges of sin. These social relations had important implications. Van den Berg (1972a) writes that 'the relationship between man and fellow man is such that it realizes itself in the nearness and distance of world and body' (p.71). In other words, others play a significant role in one's relationship to one's body and one's world. In the eyes of others, Diane felt she existed as an outcast and a sinner. Existing from this standpoint, she lived out her fantasy of punishment by alienating herself from her world and others.

Diane felt a distinct need to punish her body, signifying her body's death by cultivating an unattractive appearance. She remarked (D66):

"I cut all my hair to punk style ... I tried to make myself look even uglier. I used to wear these big ugly clothes so the nobody would look at me ... I don't know if it was to signify that I was dead because I was told I was going to die."

When asked how believing the virus was a punishment affected the way she felt about her body, Diane replied (D64,74):

"The virus was in my body and it was all over me ... I tried to clean it and scrub it. I would try and hurt my body. It was dirty ... I thought if I scraped it I might

be able to scrape some of it out.”

Diane’s body felt contaminated and impure. She engaged in cleansing rituals and deliberately inflicted pain upon her body in order to purge herself of HIV. Diane is the sinner - the outcast - and her body is the concrete realisation of that metaphor; a figured perspective of what it means for her to live with HIV. As Diane embodied the metaphor of punishment, her body became an evil and sinful container of a deadly virus.

Van den Berg (1972a) writes that ‘the body figures itself in accordance to the world in which its task lies ... it takes on a figure’, and as it does so, so is the ‘world changed by the body moving about in it’ (p.58). A disturbance in the bodily sphere alters the way in which the world appears. As an outcast and a sinner, Diane felt she could not enter into the public eye. Diane’s surroundings appeared unfriendly and inhospitable. Outside she felt defenceless, exposed and vulnerable to judgement and hurt so she remained at home where she was protected and invisible. In a sense, Diane’s world became a prison and her freedom was restricted.

According to phenomenologists, the basic characteristic of human existence is openness and receptivity. As Boss (1979) writes, it is ‘an open realm of perception’ (p.23). The body is itself an open and expansive presence to the world in that it bodies forth a particular relationship to the world. Diane’s fantasy of punishment, implied a disturbance in her capacity to relate to the world in an open and receptive manner and therefore indicated a failure to fully inhabit her world. Just as the body is an open presence to the world, so too can it close itself to the world.

Sarah’s embodiment of the heart of stone metaphor was also realised as a distancing from her world and others. Sarah’s community conceptualised HIV/AIDS as a disease afflicting sexually promiscuous individuals. For Sarah, others were described as degrading her to the lowest level of society. In relation to others, Sarah felt exposed, degraded, humiliated and ostracised. Existing from this standpoint, Sarah felt she had to have a *heart of stone* to survive the discrimination. Again this had implications for the way in which she embodied her world. To defend herself

against hurt, Sarah cultivated an emotional indifference. She remarked (S27):

“To survive the discrimination in the family I had to have a heart of stone. I mean I had to switch off - like a little button - I switch it off. I have that feeling - I feel nothing. I had to have a heart of stone because I almost had to feel nothing to survive.”

The process of cultivating an emotional indifference was likened to constructing a concrete wall (S33,35,40):

“It’s like building yourself a concrete wall...I won’t allow someone to break through that wall and I don’t want anybody there because that’s my private property... it protects me from the outside...”

Sarah’s openness to the world was obstructed by this wall which demarcated the boundaries between her world and the world of others. Sarah’s space became marginalised and her world was in a sense transformed into a battleground. In effect, Sarah’s ability to relate to others in an open and receptive manner was also impaired. Intimate, interpersonal relationships constituted a potential invasion and threat to her private world (S34, 36,37).

For the most part, these participants failed to inhabit their world from their own standpoint and were constantly aware of what others thought. Others were for Sarah the enemy, invaders, and for Diane others existed as condemners and judges of sin. To be authentic means that one is in the world from one’s own standpoint. In this instance, such a relationship was disturbed.

Considering the above, a question emerges from the research; is it possible to live authentically with HIV? The initial phase of living with HIV was largely marked by participants being caught up in the fantasies of *Das-man*. This resulted in an inability to authentically appropriate HIV as their own. Participants’ understanding of HIV was largely controlled in terms of what the

anonymous “they” interpreted HIV/AIDS to mean. Several aspects of participants’ experience pointed toward their failure to authentically embrace HIV as their own. Caught up in the fantasies propagated by society, participants were existing from the standpoint of others. This was manifest in the way in which they related to their bodies/others and world, represented in Sarah and Diane’s experience.

There did seem to come a point however, when participants took responsibility for, appropriated and affirmed HIV as their own. Such a change was augmented by participants publicly revealing their status to others and proceeding to imbibe positive metaphors with which to continue living with HIV.

5.2 Possibility of transformation

Although HIV/AIDS is often understood as a devastating illness which leads to loss and tragedy, aspects of individuals’ experience suggested that HIV presented both an opportunity and a challenge to redefine one’s outlook on life. During the interviews all participants bodied forth an extremely positive and open attitude regarding their illness. The possibility of transformation, of viewing HIV as a challenge rather than a crisis, emerged as a strong theme in the experience of living with HIV.

5.2.1 Public revelation and a sense of universality

The results showed that an opportunity ultimately arose in which participants publicly revealed their HIV status to others. The process of public revelation emerged as a strong component in counteracting much of the rejection and isolation participants experienced. All participants felt that publicly revealing the fact that they had HIV was a necessary and cathartic step in being able to cope effectively with the virus. Yalom (1985) identifies a number of therapeutic factors in group psychotherapy which have relevance in this instance. He writes that many [patients] enter [therapy] with the disquieting thought that they are unique in their wretchedness. A [patients] sense of uniqueness is often heightened by social isolation. However, upon hearing other

members disclose concerns similar to their own, they may perceive their similarity to others which inspires a deep feeling of universality (p7-9).

In relation to HIV, this sense of “universality” appeared vital. Much of the social isolation participants experienced was due to the social metaphorical connotations surrounding HIV/AIDS. Others simply failed to empathise with and understand those suffering from HIV, reacting with fear and ignorance and distancing themselves from the disease. Participants did indeed feel ‘unique in their wretchedness’. By going public, participants entered into a world with others who had HIV/AIDS; they heard stories similar to theirs and this in a sense dissolved many of their feelings of isolation and being “unique”. They encountered empathy, compassion, comfort and support and were imbued with a feeling of universality (S26; D39, 40; P17; J32, 33; M19). This sense of universality helped transform participants’ identity.

5.2.2 HIV/AIDS as challenge - fighters and educators

The feeling of sharing in a common peril seemed to be the catalyst for establishing an atmosphere of common understanding and empathy amongst those suffering from HIV. No longer did participants envision themselves as sinners and outcasts, attempting to hide the fact they harboured an evil and contaminating virus. HIV/AIDS was a challenge and many, if not all, participants envisioned themselves as fighters, educators and mentors for other sufferers of HIV/AIDS. For example, at the time interviews took place, all participants were radically active in the AIDS awareness field and spoke about their ambitions and the challenges they encountered as HIV- infected people. For instance, Diane believed having HIV provided an opportunity to realise and fulfill her dream of teaching others. She felt imbued with a sense of direction in life (D32,70,71). Jan felt that he had an obligation to fight the fact that people still thought it was sinful and evil to have HIV/AIDS. Instead of retiring, Jan had extended his work activities and become active in HIV/AIDS work (J36). Pat felt that having HIV had given him a sense of direction in life because it provided him with an opportunity to fulfil a meaningful role as educator (P64,65). Mercy (M21,22) mentioned that AIDS work provided her with a purpose and

an opportunity to help others. Sarah defined her role as both educator and fighter (S59, 60, 62, 63), and spoke of her ambition as educating others about HIV/AIDS. Every time she felt discriminated against, she took it as a challenge to educate those who were ignorant.

It is evident that by perceiving themselves as educators of, fighters for, and mentors to others suffering from HIV and AIDS, participants were imbued with a sense of meaning and a will to carry on living. They found that their task in the world was now one of fighting the discrimination, stigma and ignorance that HIV/AIDS represented. This translated into a challenge and a cause worth fighting for.

5.2.3 Towards a mindfulness of Being

For most participants their encounter with death, and the isolation, alienation and discrimination they felt throughout their experience of living with HIV, led them into a more authentic mode of existence. Their crisis translated into an opportunity for change and a renewed sense of meaning in life. Based on his work with cancer patients, Yalom (1980) writes that among the positive shifts he witnessed were an enhanced dedication to the present, an impassioned and vivid appreciation of life, and an enhanced interest in human concern. In relation to HIV, participants seemed to perceive the life surrounding them in a different light. As the results showed, temporality (lived time) was marked by a shift from a preoccupation with the future to a dedication to the present (S17,70; D34; M15). An acknowledgement of finitude seemed to lend a heightened sense of meaning and significance to the present and the pleasures that currently existed in life. All participants described an increasing appreciation and awareness of life. A new attitude of benevolence and responsiveness to others was also apparent (S69,70,71; D29; M15,16). For example, Diane referred to having HIV as a blessing in disguise, making her more sensitive and aware of others.

In line with Heidegger's (1962) understanding of authenticity, the experience of HIV seemed to move participants to a mindfulness of Being. Heidegger uses the term "resoluteness" to describe

that state in which '*Dasein* is recalled to an authentic openness, such that its awareness of the world and of others is transformed' (Parker, 1985, p.37). In other words, resoluteness is characterised by an authentic openness; being-in-the-world authentically with others. By taking responsibility for their illness and by appropriating and affirming HIV as their own rather than something inflicted upon them by others, participants seemed to embrace an attitude of resoluteness. They were able to take up their life from their own standpoint.

5.3 Coping styles

What emerged strongly throughout interviewing participants and through subsequent analysis of their data, was that learning various coping styles had been vital if they were to continue to live positively with HIV. This was realised largely in terms of relationships. For instance, some participants felt that nourishing a relationship with God was the only means of coping with their illness. Results showed that other participants spontaneously assumed a specific relationship with their virus in order to co-exist with it. In both instances, most participants formulated some kind of imaginative/metaphorical relationship with HIV which helped them to cope with their virus.

5.3.1 A spiritual response to HIV

It would seem that both a biomedical and social response to HIV/AIDS proved inadequate and at times detrimental in terms of conceptualising and dealing with the disease. Due to the fantasies propagated by practitioners and society as a whole, HIV was conceptualised as something evil, contaminating and sinful, which would lead to a physically tortured death. Bearing in mind that biomedicine provides no curative treatment for HIV/AIDS, participants were instilled with little hope of recovery and were treated with condemnation and distaste by others. It is not surprising then, that many individuals subscribed to a spiritual approach in understanding and dealing with HIV and in turn felt it to be an effective means of dealing with the illness.

Understanding HIV in terms of a spiritual metaphorical framework was most evident in the case of Diane and Pat. Rather than seek scientific explanations for their illness, Diane and Pat situated

their experience of HIV in terms of religious allegory. Lupton (1994) claims that understanding and dealing with illness in terms of religious allegory was common in the seventeenth century when illness was often seen in providential terms, in which a sense of guilt and sin were prominent. Hawkins (1984) describes the seventeenth century understanding of the meaning and uses of illness in terms of four central and interrelated concepts: the conviction that illness comes from God; the equation of sickness with sin; the belief that physical illness requires a spiritual cure; and the paradoxical notion that illness functions both as judgement and as mercy ie., that illness is a punishment for sins and at the same time an occasion for repentance (p.243).

Many aspects of Pat's experience can be understood in relation to the above mentioned concepts. Although Diane's experience of HIV corresponds at times with the above mentioned conceptualisations (for example in the way she perceives HIV as a punishment, equating sickness with sin), it is evident that attributing significance to HIV in this way did not provide a means of effectively coping with the virus. Furthermore, the implications of imagining HIV as a punishment have already been discussed.

5.3.1.1 HIV as a demon from the Devil

Pat attested that the significance he attributed to HIV helped him to cope with his illness. Pat imaginatively perceived HIV as a punishment in the form of a demon from the Devil (P34,35). Pat believed that the Devil had given women AIDS, and it was through partaking of the "forbidden fruit" that Pat sinned and contracted HIV (P61). In this instance, sickness was equated with sin.

Pat believed that his physical illness required a spiritual cure. For Pat, HIV was an occasion for repentance and he concentrated on ridding himself of the demon. Pat did this by actively nourishing the good in him which entailed engaging in activities of which God approved. This enabled Pat to separate himself from the virus and concentrate on redeeming himself.

Pat's imaginative perception of HIV had important implications for the way in which he related

to his body. Pat perceived God as the ultimate saviour, capable of performing miracles in his body. In a sense, Pat's body became a temple. He remarked (P46):

“As I treat it as a demon in my body I always emphasise that this body belongs to God and I always have to hope that God will not let the Devil destroy my body as I am a son of God...”

As long as Pat's body belonged to God he could forget that HIV existed therein and he could extricate himself from HIV. Inhabiting his body in this way, Pat described himself as bodying forth an open relationship to others and the world (P38). Pat's effort to rid himself of the demon translated into a fight between good and evil and he pictured his body as the landscape in which this fight ensued. He remarked (P53):

“It's a partnership. Me and God are working together to fight the virus. That's what is happening inside my body...we cannot be defeated by this, that's what I'm always telling myself. Me and God fighting the enemy together, fighting the Devil.”

In order to cope with HIV Pat chose to negotiate with, and work with God. Pat agreed that imagining HIV in this way helped him to be strong and positive. As was evident with Sarah and Diane, Pat's experience once again signifies the ontological import of metaphor. By saying; *“HIV is a demon from the devil”* Pat was also alluding to far more than a figure of speech. This metaphor reflected the way in which he embodied his world. It would be premature to conclude whether Pat's imaginative perception of HIV has enabled him to continue dealing effectively with the virus. However what is important and what should be emphasised is the impact metaphorical thinking about illness has on the way in which individuals constitute their worlds.

5.3.1.2 Establishing a relationship with a Higher Power

Several features of participants' experience suggested that a spiritual approach to illness was effective in helping them to maintain a positive attitude. Almost all participants spoke of the importance of establishing and sustaining a relationship with a God (D21,23,47; P31; J19, 20; M36). Having HIV meant that for the most part, participants were alienated from the world of the "they". As has been articulated, existential isolation in itself and in relation to death were some of the ultimate concerns that participants encountered. In some cases, isolation and the threat of death were dealt with by forming a relationship with God. For instance, Diane described how she did not fear death because she knew she was going straight to Heaven (D33). When she did start to feel anxious about death, God seemed to show her that he could take her any way He wanted. Yalom (1980) maintains that forming a relationship with a divine being is one way of shielding oneself from the dread of ultimate isolation. In this instance, it would seem that actively nourishing a relationship with a Higher Power counteracted much of the isolation participants have felt during their experience.

It is important to mention that a specific metaphor, that of HIV/AIDS as Leprosy (Table 2, p.112), seemed to encourage some participants to establish and nourish a relationship with God. Both Diane and Jan came to a point where they imagined HIV/AIDS as leprosy (D28,55; J47,48,49). This acted as a turning point for them, altering the way they came to understand and deal with HIV. By substituting one for the other, their perception of HIV/AIDS changed. Diane realised that God loved the lepers despite their disease. This counteracted her feelings of being a sinner and an outcast. The image of a punishing and wrathful God who had rejected and abandoned her disappeared. He became a loving and compassionate Father who held and loved the lepers. For this reason He would love those suffering from AIDS too. As Diane remarked (D28,55):

"I no longer think it's a punishment because God doesn't punish people. He loves me. He loved the lepers, He spoke to them, He held them, He touched them. He loved the lepers, He loves all the AIDS people. This was important to me ... I no longer felt like a sinner."

Jan described the lepers as being in the same predicament as individuals suffering from HIV/AIDS. They were outcasts who had to live outside the city walls. Because God loved the lepers he believed that He would not reject those with HIV and AIDS. The metaphor of HIV/AIDS as Leprosy proved very transformative because it transformed the persecutory image of God. So too did it restore these participants' sense of humanity. God became someone Jan and Diane felt they could turn to, who loved and accepted them as individuals. In a sense, this metaphor enabled Diane for example, to accept and affirm HIV as her own instead of a punishment incurred by God. In doing so, Diane's capacity to authentically inhabit both her body and world was realised. So too did her relationships with others improve.

Diane, Pat and Jan chose to actively nourish their relationship with God which helped them to live with HIV. As with Pat, Diane and Jan described themselves as negotiating and working with God in handling HIV. Diane emphasised that she refrained from negotiating any form of relationship or dialogue with her virus because she believed they might have terrible fights and the virus would end up winning (D45,46). Diane reiterated that she could not regard HIV as anything but a virus. Instead of communicating with HIV, Diane communicated with God and in doing so, what was initially embodied as an evil and contaminating virus became a "good part" of her (D28).

5.3.2 Establishing a relationship with HIV: Dialogue with the virus

Asking how participants imaginatively perceived HIV afforded important insight into the way they proceeded to live with their virus. Some participants' imaginative perceptions of HIV changed as they began to perceive HIV from their own standpoint. For example, after a period of failing to inhabit her body because it contained a threatening virus, Sarah established a relationship with HIV and no longer felt the urge to dissociate herself from her body. Instead, she emphasised that a harmonious relationship with her body would ensure survival. This is perhaps largely due to the fact that Sarah actively related to her virus.

Sarah described HIV as unpredictable - a trickster. On the one hand he was evil, deceitful and manipulative. When she felt ill, Sarah imagined that HIV was deliberately deceiving her by making her sick. Sarah responded by acknowledging HIV's manipulation and refusing to give in to her illness (S61). On the other hand, Sarah described HIV as her little voice reminding her of their mutual need to survive. As her voice, Sarah regarded HIV as neither friend nor enemy. Rather, she described herself as loving her virus (S55,57). Although Sarah was aware of the power of HIV, she did in a way establish a metaphorical space in which she and HIV could dwell. Sarah embraced her virus and felt that she managed to live positively.

Mercy pictured HIV as a special virus (M10,11,39). She considered HIV special because it sought to live in her body whilst she was alive. This inspired Mercy to fight the virus positively with the intention of keeping them both alive. For Mercy, fighting positively meant understanding HIV and learning more about it. Instead of viewing HIV as an enemy, she saw it as a friend. Together they lived in harmony and were inextricably intertwined. By imagining HIV in this way, Mercy spontaneously invited HIV to dwell in her body.

The above descriptions are instances of what David Ross-Patient and Orr (1997) would refer to as 'dialoguing with one's virus'. Establishing a 'dialogue with HIV' is deemed to be a positive and necessary framework for coping with HIV, whereby individuals spontaneously come to negotiate a metaphorical space in which to live with their virus. Patient and Orr (1997) write that 'without exception, every long term survivor of HIV infection has at some point had a dialogue with the virus in their body, and has come to a stage of mutual respect and "truce"'. This cessation of hostilities has a profound effect upon the activity of the virus which only activates when provoked. The immune benefits of this process have been documented in Kaiser (1993).

The benefits of dialoguing with HIV are considerable considering that David is one of the longest surviving HIV-infected individuals in the world. It is interesting to note that David began his dialogue with HIV long before it was established and documented as having considerable benefits. By examining David's dialogue with HIV, (section 4.3., p106) it is evident that a

specific metaphorical framework is invoked. The metaphorical framework of the fight, of victory and conquest is explicitly avoided. The relationship between David and HIV is based on mutual respect, negotiation and harmony. HIV is perceived as an intelligent and powerful life force whose prime instinct is to survive. By openly acknowledging HIV's right to survive and at the same time asserting his own right to survive, David sets up a space of mutual respect. Embracing the virus and engaging with it in a calm and rational manner instead of becoming angry and scared, is considered an extremely effective means of dealing with HIV.

The benefits of dialoguing with HIV are supported by Psychoneuroimmunology (PNI), the study of the impact of psychological factors on immunological diseases (Leiphart, 1997). PNI research has revealed that stress, depression, grief, social isolation and stigma can lead to AIDS progression, whilst other psychological states improve immunity and survival (Heyman, 1992; Lederer & Deleon, 1996; Leiphart, 1997). Coping styles which improve immunity and survival include dialoguing with HIV.

5.3.2.1 A note on HIV as personified

The way in which participants imagined HIV in terms of a personified figure, provides an interesting point for reflection (Table 3, p.113-114). Most participants spontaneously pictured HIV as an imaginative other. Both Sarah and Diane referred to, and imagined HIV as a male (S65,66; D42,43). Diane emphasised that she thought of HIV as male because it was a man that gave her the virus. The powerful, controlling and dominating quality of HIV is evident in Sarah's description of the virus (S66):

"I only know that he is wearing black. I think he's very huge. If I had to put him in a human body he's about seven feet tall and he's built very hefty and when I think about it he's always laughing - not smiling, laughing as if he's teasing. His mouth is always open, laughing, something like; I've got you, you can't get rid of me, I've got you."

Other participants did not allude to the gender of HIV although Pat did refer to HIV as demonic bisexual ants. In fact it is interesting that both Sarah and Pat experienced HIV as feasting ants. Jan avoided thinking about HIV metaphorically. To him the virus was a powerful life force which should not be thought of as any different to other diseases. Although Jan did not think of HIV in terms of a definite “other”, he did mention that the virus could be perceived of as special (J52,53). Jan believed that if he had been infected in a loving sexual act, he would have perceived the virus as special rather than evil. This raises an interesting point. It suggests that people may perceive HIV differently depending on the way in which they contracted the virus.

5.4 Evaluation and concluding comments

5.4.1 The validity and contribution of an imaginative response to illness

Kleinman (1988) writes that ‘the study of the experience of illness has something fundamental to teach us about the human condition, with its universal suffering and death’ (p.xiii). He proposes that medicine should attend to the individual’s subjective experience of illness rather than ordering their experience in terms of the concept of disease. To perceive a patient as a diseased object or a “statistic” is to deny the humanity of those who suffer. Because the rate of HIV- infection is increasing at a phenomenal pace, those who suffer from the illness are readily regarded as “statistics”. During the course of this research, participants emphasised their need to be heard. For example Diane remarked, “Statistics don’t mean anything. Behind every figure there is a person with feelings, that hurts, that cries - that feels.” Diane’s words in a sense captured the essential aim of this research. This thesis was primarily concerned with offering an alternative way of envisioning illness so that those suffering from illness could be heard. Metaphor was chosen as the language best suited to conveying the depth of each individual’s experience.

Hillman would say that all access to the world is structured imaginatively and that as human beings we are primarily image makers. He writes that ‘imagination is the only reality, directly

presented, immediately felt' (1977, p.86). Such a view is authenticated by Heidegger and Romanyshyn who acknowledge that imagination is the definitive characteristic of human being, our perceptions being fundamentally imaginative understandings. An adequate understanding of psychological experience thus entails exploring the images and fantasies that shape reality. Much of the essence of what it meant for participants to live with HIV was captured by working from this standpoint. Participants also seemed to feel more comfortable about expressing themselves when they were invited to speak metaphorically.

Phenomenology was an invaluable approach for accessing the depth of the images and metaphors participants described, because it respected the validity of each individual's lived experience of HIV. Certain conceptual aspects of phenomenological psychology were drawn upon to situate and amplify participants' experience. To quote Romanyshyn (1982), "Psychological experience is visible through the things of the world" (p.38). In accordance with such a view, phenomenology seeks to open up a world that matters and which must be understood. As stipulated in the literature review, phenomenological writers including Boss (1979), Heidegger (1980), Kruger (1988), and Van den Berg (1972a & b), emphasise that we cannot begin to understand human existence by envisioning human beings as encapsulated subjectivities, separated from the world and inhabiting a purely physiological body. As Van den Berg (1972a) writes, 'we gain insight into another person, his condition, nature, habits or disturbances ... when we inquire about his world' (p.39), when we make 'an analysis of the "landscape" within which he demonstrates, explains and reveals himself' (1955, cit. in Romanyshyn, 1984, p.102). The fantasies and metaphors mediating participants' experience were accessed by exploring the "landscape" in which each participant dwelt and by conceptualising the body as a meaning creating existence which speaks this meaning through the voice of metaphor.

It is very difficult to articulate accurately the immediacy of experience. Some feelings and experiences are too elusive, too inchoate for logical and technical explanation. Furthermore, when one attempts to give a factual account of experience, it somehow detracts from the meaning and the depth of that experience. As noted in the literature review, the biomedical model

concentrates on understanding and treating disease in terms of biological disorder and in effect isolates the emotional significance of disease (Kirmayer, 1988). The medical model limits our understanding of the nature of illness and it is worth contemplating Baron's (cit. in Diekema 1989, p.20) comments once again:

Taking disease to be an anatomic or technologic fact, we are led further away from our ability to understand disease in human terms ... entire aspects of the phenomenon of illness remain inaccessible or incomprehensible to us.

The medical model is essentially concerned with categorising and understanding disease in a technologic, factual manner and thus calls one to remove oneself from the patient's world. Many aspects of participants' experience affirmed that one does not really experience illness factually or in strict physiological terms (a point emphasised by Scheper- Hughes & Lock, 1987). A recollection of Sarah's experience of HIV in her bloodstream as thousands of feasting ants authenticates this viewpoint (S51,52,53):

“They explained that HIV was in my bloodstream ... it was then that I had thousands and thousands of ants eating me all the time ... I wasn't in control ... It was my way of seeing the HIV virus eating in my blood, the black ants trying to kill me because AIDS kills, feasting and taking over.”

It is much easier to convey and effectively grasp an experience when it is relayed imaginatively or metaphorically, when an individual tells you, “This is what it felt *like*.” It is the imagination that reveals the unique nature of each individual's suffering. How much more do we sense and relate to Sarah's fear and anxiety by remaining open to the voice of metaphor. Suddenly we begin to gain a direct and vivid sense of what it means to experience HIV because metaphor is a very evocative and animating means of expression.

In illness the body is, and can no longer be experienced as it once was. Kruger (1988, p.40)

writes:

Man becomes aware of the fact he has a body only when the body becomes an object for him; this happens only under certain circumstances, eg, when he is being medically examined or when he knows that he is sick.

In other words, and as Van den Berg (1972a) points out, 'a disturbance, disease has to enter the body one *is* to make the body one *has* come into existence' (p.50). In the experience of HIV, participants were called back to their bodies. In illness the body took on a significance not previously acquired. Upon being diagnosed with HIV, the body seemed to speak of its afflictions metaphorically. Upon describing HIV as a demon in the form of an ant, Pat (P25,26) remarked:

"I had a picture of a person who is HIV and I looked at myself and even the symptoms of HIV in my body were really frustrating me. I felt like it was eating away at me so I concluded that it could be that the virus is something like an ant which is moving around in my body. That is one of the things that really tortured me."

Once again, HIV was not experienced in a physiological sense. It was imaginatively embodied. It was by listening to how individuals spoke of their bodily felt experience in an imaginative way that a sense of what it felt like to experience HIV was obtained. These are but a few examples of the many instances in which the body spoke of its afflictions in a way that biomedicine tends to forget.

5.4.2 Limitations and suggestions for further research

Stones (1979) quotes Colaizzi (1978, p.70) in saying that since 'the structure of any *Dasein* is such that it never "arrives" but is always "on the way"', it is incumbent on the phenomenological researcher to recognise 'that research can never exhaust the investigated phenomenon, that

research can never be complete'. It is acknowledged that the metaphors identified in this study revealed a variety of different meanings, many of which may be subject to different interpretations and in this sense the research cannot profess to being "complete". The interpretations of the findings in this study drew their validity from exercising a systematic and rigorous phenomenological approach, a fidelity at all times to immediate and imaginative experience. Rather than provide a host of well defined explanations and answers, this study was more concerned with recapturing a way of seeing that is oftentimes forgotten. In effect, it is perhaps accurate to say that this study provides a starting point from which to continue studies grounded in this approach. The following suggestions delineate possible areas for future research:

The possibility of transformation emerged as an important theme in this study. Often HIV/AIDS is perceived in terms of crisis and tragedy and the opportunity for growth and transformation is obscured. A study conducted by Mueller, Medina, Dunbar & Wolf (1997) revealed that significant positive changes may take place in the social, psychological and spiritual lives of HIV- infected individuals. However, the psychological growth people with HIV experience is often overlooked. Understanding this growth process and the transformation individuals may experience is deemed a significant area of study.

Since metaphor is a powerful constituent of meaning, it presents a means of effecting change in the way individuals understand and deal with illness. It may therefore be pertinent to explore the metaphors that therapists/counsellors and patients make use of in a therapy/counselling relationship. It would be useful to explore which metaphors are transformative and challenge a positive mode of being.

One of the difficulties encountered in this research was that participants were at different stages of processing their illness. This made it difficult to thematically categorise their experience because each experience was truly unique. In terms of prognosis, four participants, Sarah, Diane, Mercy and Jan had been diagnosed between 1991-1994. Pat was only diagnosed in 1996, whilst

David proved the oldest survivor of HIV, his diagnosis being in 1983. Because each participant's prognosis of HIV differed, it was evident that each individual was at a different stage of accepting their illness. Their articulated experience reflected this. For instance, the researcher felt that had Pat been interviewed in two years time, further and perhaps alternative meanings might have been revealed. Based on these observations, a suggestion for further research is that of interviewing long term non progressors who have actively engaged in dialogue with their virus. Exploring this metaphorical relationship could elicit some important commentary on the positive use of metaphor in adjusting to and living with HIV.

Although the sample group for this research reflected differences in terms of age, gender and culture, all six participants were very active in the AIDS awareness field. Indeed, it would seem that their role as educator/fighter and mentor influenced the manner in which they inhabited their world, related to and dealt with HIV. It may be of interest to interview HIV-infected individuals who are not active in the AIDS awareness field. Such an exploration may reveal a range of alternative metaphorical frameworks within which individuals situate their experience of HIV.

This study revealed that the socio-cultural context from which participants emanated, influenced the way in which HIV/AIDS was understood. Three participants emanated from an African background and this cultural variation served to reveal some interesting themes. For instance, two participants recounted how HIV/AIDS was perceived as a myth in their community. The data did not yield sufficient information to pursue the implications of this metaphor in any great depth. However, it is an important theme and one which could further be explored. Exploring the metaphors individuals from different cultures use to understand HIV/AIDS, could contribute towards a shared understanding of what HIV/AIDS means for different people.

Finally, the study of metaphor need not be confined to the phenomenon of illness but may be explored in all areas of human experience.

5.5 Concluding comments

United Nations figures reveal that 1 in every 100 sexually active adults aged between 15 - 49 harbours HIV (Anon, 1997/1998). In view of these statistics there rests upon society an urgent obligation. No longer can those suffering from HIV/AIDS continue to be ignored, or subjected to discrimination and rejection. This study has shown that metaphorical thinking about HIV/AIDS impacts greatly on the way in which participants come to conceptualise and deal with their illness. Some of the social metaphors identified in this study were seen to contribute to the social isolation, stigma and stress experienced by HIV- infected people. These metaphors could very well lead to AIDS progression. If the way one thinks of and imagines HIV has important consequences for how effectively one is able to live with HIV, it follows that certain metaphors can enhance well-being, the quality of social relations, as well as immunity and survival, whilst others should be avoided.

For those not directly suffering from HIV/AIDS, the experience often remains an enigma, something threatening and unfamiliar. That which is unfamiliar often breeds misunderstanding and fear. Much of the fear, ignorance and discrimination surrounding HIV/AIDS reflects a failure to participate in the "lived universe" of those who are ill. Yet entering into this world is the very thing needed to remove the divide that oftentimes exists. Metaphor presents itself as a powerful mediator, bridging the divide between worlds of meaning. Metaphor not only provides a bridge between the known and unknown for the individual, but a bridge between individuals. The voice of metaphor opens up a world and invites one to share in that which might otherwise remain intangible. It is by finding a common ground through fantasy, through image, that we might indeed begin to build and come to share worlds of compassion, significance and meaning.

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APPENDIX A

ETHICAL PROTOCOL

Researcher's name	Julia Claire Cardo
Status of Researcher	Psychology Masters Student Rhodes University Grahamstown

Project Title	HIV and Metaphor: An imaginative response to illness
Purpose of project	To achieve an understanding of what it means to live with HIV

I hereby consent to participate in this study upon the following understanding:

- The guiding rule of this research project is to remain at all times faithful to each participant's experience of HIV as it is lived.
- Participant's will be thoroughly briefed on the nature and purpose of this research project prior to commencement.
- The process of faithfully describing and articulating participants' experience shall be conducted in such a way as to ultimately deepen the participants' access to the nature of their experience.
- Data collection will include audio-taped recordings.
- If at any time participants feel unable to continue being interviewed they are free to leave.
- Meaning is to be sought through a continuous dialogue between researcher and participants. Throughout the process of data collection and transcription, participants will be invited to evaluate whether their statements accord with the researcher's interpretations.
- In the written report, participants' names will be replaced by pseudonyms in an attempt to secure anonymity and confidentiality.

Signed.....

Date.....

Appendix B

Diane: Organization of data

White female, aged 34

1) I was diagnosed six years ago and it wasn't because I went for a blood test; I was doing my duty and I went to go and donate blood.

Diane gave blood out of duty rather than necessity.

2) I knew everything about AIDS but I wasn't going to get it because I was a good girl. I didn't sleep around or do anything bad. I was a typical mommy who stayed at home and all that hogwash that went with it.

Diane implies that she would not contract AIDS because she was of virtuous, obedient and morally sound character.

3) I donated blood and about a week later the blood bank contacted me and said that they had lost my blood and they needed to take some more. They did it and a week later they came and saw me in my own home.

Diane was visited by the blood bank in the privacy of her home.

4) They read me a list of seven questions that I had to answer yes to. Have you got night sweats, diarrhoea...?, things like that. I answered yes to five of them and she said to me, "You've got AIDS, you're going to die, deal with it." Those were her words.

Upon informing Diane of her results, the blood bank imparted a tactless and fatalistic message. Diane was explicitly informed she had AIDS which would bring with it certain death.

5) So I expected to die now, right then and there. I had a daughter of six years old. I

Because she felt death would be instantaneous, Diane made practical

made arrangements for her to go and live with some people, I prayed to God to forgive all my sins and I laid down and I waited to die - literally. I thought it was going to be instantaneous. I thought it was final.

6) At that stage I felt numb, I didn't feel anything. By the following morning I still hadn't died so I didn't believe them. After about two weeks I realised; well first of all I don't have AIDS and I don't have HIV because I didn't die.

7) So I had another blood test. I made sure I got counselling before the test and it came back that I was still HIV positive and then I started bartering with God. I promised him I would never shout at my daughter again, I would go to church every Sunday and I would be the perfect mom if He'd take it away.

Did you believe it could be taken away?

8) Yes, but it never happened. But then again I never kept my side of the bargain. Then I went through denial. I didn't believe it. I went through anger. If I could have got a gun I think I would have shot my ex-

preparations for her death.

A feeling of initial numbness was supplanted by a feeling of disbelief. Diane denied the existence of HIV because she had not yet succumbed to death.

Requiring confirmation of her diagnosis, Diane received another blood test. She proceeded to bargain with God in the hope that He might remove the virus.

Diane experienced feelings of denial, disbelief and anger. Her anger manifested in a desire to murder her husband from whom she contracted the virus

husband. I wouldn't have batted an eyelid. I forgot the one important rule - all his sleeping partners became mine.

Did you have a picture of HIV/AIDS before you were diagnosed?

9) They vary. Before I was diagnosed, there's that song, "Good girls go to heaven, bad girls go everywhere", and I was a good girl. As far as I was concerned only bad girls - promiscuous people, whores and prostitutes were the only ones that got it. Drug addicts didn't even fall into my lifestyle. It didn't affect me, and I worked for a medical doctor so it was far away.

10) After I was diagnosed I saw myself as being a bad girl because I had made that category myself. It took about two and a half years to realise that I was not a bad girl, that I'm a normal person and I look like everybody else.

11) It got to that stage where I'd look around and anybody that started to get thin I'd think; aah they've got AIDS.

How did others react to you?

12) First of all I had to tell my boss because

Diane derived her first picture/image of AIDS from a song, the title of which introduces a play of polarity - innocence, guilt, virtue and promiscuity. Diane defined HIV as a disease affecting sexually and morally deviant individuals the antithesis of how she perceived herself.

After her diagnosis, Diane's perception of herself changed to that of a bad girl.

For a long time Diane experienced a paranoic tendency to identify AIDS with every person she saw.

The medical profession perpetuated Diane's

I worked with patients. He said, "No it's impossible, you can't have it because good people don't get it." The medical profession believes it as well, that good girls don't get it.

13) Then I told my parents and my two brothers and I thought I'd get rejected by my one brother who's a very big Christian. He is actually the one who supports me the most. My parents were the ones that rejected me. If I got invited to supper it's lovely because first of all I got out of washing the dishes. I would be given paper plates and knives, forks and cups. Then I was asked very nicely not to talk to their friends because they don't want their friends exposed to it and they would hate it if they were to find out I was HIV. I felt embarrassed and rejected.

Can you tell me more about how you felt?

14) In the beginning a lot of anger. I hated them I really did. Any piece of information I could get about AIDS I underlined it and I posted it express post. I was very angry and ignored them. I cannot educate them because we stay so far apart. It's an impossible task.

imaginative perception of HIV/AIDS by supporting her notion that AIDS does not affect morally virtuous individuals.

Diane experienced rejection from her parents. They treated her like an outcast and she felt humiliated and ostracised.

Diane felt immense anger and responded to her parent's rejection by ignoring them.

15) Because they rejected me I put it on the whole society. I judged the whole society as rejection which was actually very untrue. It's just like people judge people who are HIV - I judged a whole community. I thought the whole community would turn against me. It's not like that.

Are you in a relationship at the moment?

16) Yes, nothing has changed. My life is as normal as it can be. In the beginning I didn't want to get married. I was very scared and I live with that fear everyday, that I can pass it on and give it to my husband. It's a fear of infection. The only thing is, I'm very careful. I don't kiss if I have thrush. I have a normal sex life and we always use condoms. I can understand why teenagers say it's a put off because it's like - wait, hold the bus, gotta get the condom. We make a joke of it. He says, "I told you I don't want anymore kids" and then we say, "Ok get the condom." We make a joke out of it which doesn't concentrate on the AIDS. It relieves all that tension.

Tell me about going public

17) Don't laugh! At that stage I wasn't a very good Christian. It was about one to one

Diane's first experience of familial rejection, influenced her subsequent perception of others. She imagined the entire community rejecting her. In hindsight, Diane recognises this was her imaginative perception.

Diane is presently involved in an intimate, sexual relationship. She still possesses an intense fear of infecting another with HIV. Diane injects humour into intimate, sexual encounters. This is to alleviate the anxiety the possibility of infection engenders.

Before her religious experience occurred, Sarah felt angry and disillusioned with God

and a half years ago. I was very angry with God because everything was going wrong and I felt that maybe death would be better. God always says, "Ask and you shall receive", and I didn't believe it anymore. I tried to find a passage in the Bible and I couldn't and I thought, to hell with it and I threw my Bible down. I'm not a person who believes in miracles or God appearing, but soon my room became very bright, so bright, and God gave me the speech word for word, my whole speech. It was as though the roof had caved in, as though the roof was missing. He told me what I would say; that I would talk on a certain day and at what time and where. He told me everything. It was through an angel. I could hear all the words and there was just this bright light. It was a very hard voice - like a rumbling voice - but yet quiet. I can't explain it. When it was finished it went back to normal - the lights and things - and I wrote the whole speech down. I could still remember it word for word

How did you feel?

18) I was scared because things like this don't happen to me. I felt I was going behind my husband's back in going public. I

and possessed no faith in Him. God then miraculously appeared to her and informed her that she would publicly address her community about HIV.

Despite feeling fearful and guilty for betraying her husband in going public, Diane felt compelled to carry out God's

knew I had to do it but I didn't know why. Like my dad telling me to do something and you don't contradict him, you just do it without asking any questions.

19) There was this service and I spoke. I was petrified but the first reaction was people giving me a hug and making a point of remembering my name. I had thought - would I be remembered as the lady with AIDS or would I be known as Diane?

20) Somehow, because I had obeyed God, all the things started to change. The following day people were delivering clothes and food. That's when I truly and hopelessly believed in God. I always knew that God was there. I take my problems to him but then I hold on to them and worry about them. Now I just give them to him.

21) My belief in God has a lot to do with how positive I am. God has made it very clear that he can take me anyway he wants. I believe God tells me he can take me any way he wants to. A year ago I was convinced I was going to die of AIDS. I made an appointment to go and see the counsellor and off I go and there was this

word. Diane described God as a father figure who should be obeyed without question.

Diane felt fearful and anxious before publicly imparting her story, yet she was responded to with warmth and affection.

A turning point was reached where Diane chose to invest her faith in God and trust him wholeheartedly.

For Diane, living positively with HIV is tied to a firm belief in God. When Diane feels death from AIDS to be an impending certainty, God seems to give her a sign that she will not necessarily die of AIDS,

car that came out of the parking bay from nowhere and hit us. I had an iron bar that went through my leg and I was in hospital. Then I said, "Sorry God, I believe that I don't have to die from AIDS - I can die from anything - you showed me." Then about a month later I still got this doubt again. I decided to treat my daughter to the ice - rink. As we got to Durban we went across the road and a taxi skipped the red light and hit us. And I got out and I got on my knees and I said, "I'm sorry God, I believe you 100%." After that I made sure I walked everywhere!

So as soon as doubt creeps in God seems to say...

22) He's telling me that He's God and just because I've got HIV it's not necessarily what I'm going to die of. He can take me anyway he wants and whenever He wants to. This story of, I've only got 6 years or 10 years according to the AIDS lifespan - I stop believing that. I believe that He will take me when He's ready to take me. I mean you don't get warnings twice in a row.

How does that make you feel?

23) Well I feel safe in a way because I know

Diane implicitly believes that God controls and dictates to her, her fate.

Diane feels secure in God's care and love.

God is watching over me and He wants me to carry on living my life as I should - as best I can. He's there looking after me and that makes me feel loved.

Those times when you get doubt...

24) It's when I'm sick and I've got flu and pneumonia and it becomes too much. I start to panic. There's no time left and there's still so much I have to tell my daughter. She's got cards up until she's twenty one. My husband knows where they are so if I die tomorrow he will carry on giving them to her until she's twenty one. I actually organised that after I was diagnosed. I prepared to die. I wrote for her twelfth birthday about menstruation - this happens....that happens. I got books on menstruation for her twelfth birthday.

So you prepared for all the years ahead?

25) Yes. At that stage I was alone. I wasn't re-married. It was just her and I. I had to make arrangements for her. My biggest fear was leaving her. If I didn't have a kid I don't think it would have bugged me as much, no - one to care for.

Has your relationship with God been your

When Diane feels sick she begins to feel a sense of urgency and anxiousness regarding time - particularly the future.

Diane was, and continues to be fearful of the impact her death will have upon her daughter.

source of strength?

26) I think in the last two years - yes. Before that I didn't want to know God because I was angry with him.

After a period of being angry with God, Diane now feels her relationship with Him to be her source of strength.

27) I divorced my husband after I got tired of him sleeping around and actually my daughter who was then five years old asked me to divorce him. Then I knew it was time. I found out later that he had been molesting her. She had to go for HIV testing and we waited for three weeks for the results. Mine - they just came and told me I was going to die - my daughter's was agony. She was negative. I believed it was a punishment for getting divorced because the Bible condemns divorce.

Diane divorced her husband on account of infidelity and child molestation. She believed HIV was her punishment for divorcing him.

28) I no longer think it's a punishment because God doesn't punish people. He loves me. He loved the lepers, He spoke to them, He held them, He touched them. Someone actually changed that word leper into AIDS victim for me to help me to get through it. It's no longer a punishment. It's a part of me and it's a good part.

At present, Diane does not believe HIV is a punishment from God. She appropriates HIV as a positive part of herself. The Biblical story of God tending to the lepers inspired Diane to perceive God as a loving and compassionate father.

Good part?

29) Yes because it's made me more aware of

Diane feels that living with HIV has made

people. I've become more sensitive to people's needs. Then I was concerned about my own life. I was always running around and I forgot about other people. Now I've got time for others.

30) If people can see me projecting myself as a positive person maybe I can encourage others - even if it's just one person. It's important to lose that stigma because then people will come out more. The rest of the population will then realise how serious the problem is. By the year two thousand it's no longer an HIV pandemic but an AIDS pandemic. Then we are going to see everybody - an eye - opener.

31) Statistics don't mean anything. Behind every figure there's a person with feelings that hurts, that cries. But we are so wrapped up in the statistics. Instead of saying 23% ... there are so many ... *people*. These *people* - we - need to be seen and heard.

Do you feel your role is educating others and fighting the discrimination surrounding HIV/AIDS?

32) Definitely - yes. I am dedicating myself to teaching people about the virus and

her more attentive and responsive to others.

Diane feels motivated to educate others about HIV/AIDS in order to alleviate the stigma marking the disease.

Diane feels statistics are meaningless because they conceal the humanity of each person suffering from HIV/AIDS.

Diane perceives herself as both educator and fighter. She finds this role personally

AIDS. Anywhere - like I go to schools and churches. I find it very rewarding, especially if someone comes up to me and says, "You know I really found that interesting and thank you for coming to speak to us". It's just so important that people come to learn about this disease instead of hiding behind fear and ignorance. If I can teach even a handle full of people - then I will be happy.

meaningful and rewarding.

33)It scares me not of dying but what I'm leaving behind. I'm leaving a daughter who's very insecure at the moment and very scared. I've accepted death and I've dealt with dying. I know where I'm going - I'm going straight to Heaven. I've made peace with death - I'm not afraid of dying. I'm just afraid of leaving my daughter.

Diane feels that she has accepted and made peace with death, yet she is fearful and anxious of leaving behind her dependents.

So the future appears?

34)Wonderful. I'm going to see my daughter get married and my grandchild. I'm optimistic and I'm positive. If I keep on thinking that I'm going to die tomorrow it obviously will happen. I focus on the present and live my life to the full - for mine and my daughter's sake. But I honestly feel happy when I think of the future because I feel I'm living today as best as I can.

Diane feels an enhanced sense of living fully in the immediate present and perceives the future in a positive and meaningful light.

So you really seem to live positively?

35) Yes. I don't panic because I don't live for my disease. I started going to support groups and the minute I walked in the door nobody asked me what my name was. They wanted to know my CD4 count. I had no idea what they were talking about. I'd never had a CD4 count, I didn't even know what it was. Then they kept on ... this happens at this stage ... it wasn't for me.

36) If I get diarrhoea, I think; what did I eat last night? If I get a flu bug then I think; well it's a common thing, it's all the way around me. I think of everything else excepting the virus. If I have to live according to this was caused by the virus - I don't know if I would have made it as long as what I have now.

37) I wouldn't say I deny it. I know it's there. There are times when I look in the mirror and I see my swollen glands. I am aware that the virus is there. I get permanent thrush. But I don't let it play a major role in my life. Even though I work with AIDS all day long, it's a part of my life, it's not my whole life. I've made that a point since the beginning. Some people live for their virus,

Upon visiting a support group Diane felt like a diseased object rather than a person.

For Diane, it is important not to attribute every illness she gets to HIV. She avoids being consumed by her virus.

Diane is aware of the physical manifestations of her virus yet she does not dwell on them.

knowing everything about it. I must be one of the most ignorant people around because I don't know everything about my illness. I make a point of not knowing everything about it because then it's going to cause me to live for it. I have the mind set that I am HIV infected not affected.

So it's not the whole of you?

38) No. AIDS must be taken seriously because AIDS kills and it's not easy at the end. It's not like straightforward, I walk in front of a bus and the bus kills me and I'm dead. There's suffering. I don't know if I can bare to have my daughter watch this, if she or daddy would be able to cope. Those are the things that worry me more than anything else.

Diane acknowledges the severity of AIDS and is anxious that her daughter be witness to the suffering that AIDS brings.

It would seem that other HIV positive people did not give you support or comfort...

39) Well the support group certainly didn't but that's not true for everyone. I mean I've met a lot of AIDS and HIV sufferers who have been incredibly supportive and kind - people who've really helped me.

Diane has met a number of supportive AIDS and HIV sufferers who have helped her.

Is this important?

40) Well for me personally it helped a great deal. Sometimes people can be understanding but it's not the same when they've also been through the same thing as you. That's what I've found great - people really knowing how you feel. Yes, I would say that meeting other AIDS sufferers has been a source of strength to me.

Diane encountered a common understanding amongst other HIV sufferers because they had been through the same experience. This proved to be source of strength for Diane.

Do you ever picture or imagine the virus in a particular way?

41) I never pictured the actual virus in a certain way and I still haven't. It's just something inside me, somewhere, and it's a part of my life, it's not my whole life. I don't see it as a person who I talk to.

Diane neither imaginatively perceives of, nor communicates with the virus in any concrete way.

42) If I had to picture it, it's a horrible little gaw gaw ... a little man. He's a baddy - a man figure - creeping all the time. He's eating up and gobbling, just gobbling up everything. He has little legs and little arms. It's not his hands that pick up - it's his whole body.

Diane spontaneously imagines HIV as a small, greedy man who consumes everything.

A man?

43) Of course, it was a man that gave it to me. I imagine my virus as a *he*. That's the

Diane imagines HIV as masculine because she contracted the virus from a male.

only way I've thought about it. He looks like the jelly tot man because he just gobbles - like pac man.

44) Or a worm if it was an animal - long and thin. Can you imagine how many T-cells can get inside a worm? It's so long it can swallow up quite a bit. I haven't really thought about it but I know my virus is like that. They're there and the next minute they're gone and he's on top. That's all.

45) As far as I'm concerned my virus is not a person. It's just something inside of me. I think for me personally, if I have to start thinking of it as a person and arguing with it, it wouldn't work. I can be very bitchy and I can be very stubborn and I can just imagine the big fights me and my virus would have. The virus would probably end up winning. First of all I also keep very quiet and soft. I eat it all up so the virus would have enough time to just about gobble me all up. Then I'd explode and maybe get a few cells back. But I think the virus would win if I had to talk to it because I'm very soft. I'm the person who says yes dear, no dear, three bags full dear.

Diane believes HIV is akin to a long, thin worm consuming T-cells.

Diane feels that her temperament does not predispose her to actively engaging in dialogue with HIV. Active dialogue would materialise into an argument and fight with HIV the victor.

46)It's not a person to me and so I don't argue with it or make it part of my life. I know of people who do. It reminds me of my childhood friends - those invisible friends. If I have to start talking to my virus everybody will think I'm mad.

Diane refrains from actively communicating with her virus.

47)It's all just different ways of dealing with it. Mine I actually got from going through God. I deal with it that way. It's the only way I can deal with it. I can't deal with it by talking to it. I'm not that creative.

Diane's relationship with God enables her to cope with HIV.

Clarificatory Interview.

You said that you "laid down and you waited to die".

48)The moment they told me I felt fine. I kept on thinking; it can't be me, it must be wrong, I'm not sick. By the time I got home I got past that stage and I laid down and I just waited to die. You know when they bury you in your coffin? I lay down straight, with my hands folded on my chest. I lay down like that with my blanket pulled up to my chin just waiting and it didn't happen.

Diane initially experienced disbelief upon hearing her diagnosis.¹ Later, Diane embodied the metaphor of immediate death by figuring her body as a corpse and awaiting her death.

You said you had a second diagnosis.

49)I decided I couldn't have it because I didn't die like they told me I would. I went through a long period of denial where I just didn't believe it. They were wrong and I was fine. Eventually I did go and have a test and I still wouldn't believe it. I wanted to see it on paper - in black and white. Sometimes today when I feel so well I still can't believe it. I have to open my draw and I take out this piece of paper that says I am HIV positive. I need to have that proof.

You said you started to barter with God.

50)I believed it was a punishment from God. I even told God that I would go back to my ex-husband. It took a long time to believe that it wasn't a punishment.

How did you feel when you imagined the virus was a punishment?

51)It stopped me from being a person. I couldn't love anymore because I was condemned. Talking to people wouldn't ease my punishment, it would make my punishment worse because more and more people would know what I've done and God's punishment would become worse.

Diane denied that she had HIV after the blood bank's prediction of immediate death failed to materialise. Eventually she required certainty of her results. At times Diane still requires confirmation that she is HIV positive.

Diane believed HIV was a punishment from God. She was prepared to compromise herself in the hope that God might divest her of her punishment.

Feeling like a condemned woman, Diane was fearful of exposing herself to others. She felt unable to express human qualities such as compassion and love, and failed to engage on an interpersonal level.

Did you feel like a sinner?

52) Worse than a sinner. I think the only way I could have got rid of that punishment would have been to have gone back to my ex-husband which I didn't want to do, or to have been crucified like Jesus. That's how bad I felt.

53) To be rejected by God shattered my faith. It took a long time to build up that faith again. Besides my family and friends turning away from me, in my eyes God had turned away.

54) It took one person to take that part out of the Bible about the leper and change that to AIDS.

How did that help you?

55) It helped me because then I believed that we had a loving father. I believed that He would never punish us like that, never turn His back on me. He would love me even more. It made me believe that He's a loving father and that He still loved me - it doesn't matter what I've got. He loved the lepers, He loves all the AIDS people. This was important to be because it made me feel welcome and no longer like a sinner.

Diane sought redemption through crucifixion.

Diane felt utterly rejected and abandoned by God.

Perceiving AIDS as Leprosy would mark a turning point in Diane's experience of HIV.

When the Biblical story of the lepers was substituted with AIDS, Diane's perception of God changed. The image of a punishing and wrathful God was supplanted by a loving, tender and compassionate father figure. Diane felt accepted and her feelings of sin and guilt were allayed.

56) The man who changed every leper word to AIDS was a catholic priest. He was everything I hated. I hated the Catholic Church. They never accepted my marriage to my ex - husband because he had been divorced. As far as they were concerned I was living a life of sin. When I got HIV I turned to the Catholic Church and I'm still waiting for them. If they'd come to see me I don't think I would have got as bad as what I did - believing it was my punishment. They made me feel like a sinner, as if I was a promiscuous person. They rejected me so I took that as what God would do and did to me.

So you in fact believed that God could give you this as a punishment?

57) Yes. Now it's ridiculous but at that time you couldn't convince me otherwise.

You said previously that you experienced anger in relation to your ex - husband?

58) I was angry with him but I was also angry at myself for being so stupid, for falling for the one rule that I should have known. The only anger that I felt towards him was hoping that he would come and collect my daughter. I really prayed that he

Diane felt immense hatred toward the Catholic Church. They perceived Diane as a sinner for divorcing her husband and proceeded to reject her because of HIV. This intensified Diane's feelings of guilt, sin and isolation.

Diane was convinced that HIV was a punishment from God.

Diane felt angry at both herself and her husband. Her feelings of anger toward her husband manifested in a desire to murder him.

would come and I prayed that I could get a gun at the same time so I could shoot him.

59) I wasn't really bothered if I spent my life in jail because as far as I was concerned my life was over anyway. I was going to die. So if I shoot him at least we'd both be dead and I wouldn't have gone to jail straight away. I would have shot him and had the satisfaction of seeing him die. I wanted him to die in front of me and I wanted him to die so that I could see something that I'd inflicted on him. He inflicted this on me and it's not like he gave it to me and I died overnight. It's something that I have to live with for maybe ten years, it wasn't instant. I wanted to shoot him and let him lie there and I promise you I wouldn't have helped him. That's how angry I was with him.

You say you wouldn't have minded going to jail?

60) I was going to die very shortly. To me the virus was a death sentence. I was told it was - you're going to die they said. The anger stayed with me until after the story of I'm not being punished by God.

61) Then I would go through bouts of denial

Diane's deep feelings of anger and injustice motivated her desire to punish her husband. She wished to murder him and did not fear the consequences of imprisonment. Diane felt this would prove a satisfying endeavour.

To Diane, HIV was synonymous with a death sentence. This metaphor was propagated by the blood bank.

Diane experienced a plethora of feelings

and then depression and then I'd feel guilty. I'd feel sorry for him - maybe he didn't know that he had it when he slept around.

You said that "after I was diagnosed I saw myself as a bad girl".

62) Feeling like a sinner and feeling mostly like a prostitute. I had been judgemental because I had thought that either drug users or prostitutes get it. Because the Church rejected me I felt even worse. If I hadn't thought of myself as a "bad girl" then I would have just been a person with AIDS.

What was it like, feeling like a bad girl?

63) With me it all boiled down to punishment. I already had so much guilt about getting divorced.

How did you feel about your body?

64) I tried to clean it and scrub it. I'd go crazy and take the soap and scrub my body and hope that worked. This was three/four months after I was diagnosed. Then I knew I wasn't going to die straight away. It would come in bouts. I would sit in the bath, the water boiling, boiling hot and I would get in and scrub myself as though I had been raped and was dirty all over. I would scrub it and

including denial, depression and guilt.

Diane felt immoral. The church's rejection intensified Diane's feelings of guilt and sin.

Diane felt guilty about her divorce.

Diane's body felt contaminated and impure. In order to purge herself of HIV she fervently tried to cleanse and disinfect her body.

I'd actually be raw.

65) I would try and hurt my body. I tried to commit suicide, it didn't work. I would do horrible things like I'd sit with my long nails and dig my skin in and it would be blue or red or bleeding. I would carry on doing that just to hurt it and maybe to dig it out. It was dirty. It didn't feel clean. I thought if I scraped it I might be able to scrape some of it out.

66) I cut all my hair to punk style, short, short. I tried to make myself look even uglier I think. I used to wear these big, ugly clothes so that nobody would look at me. I thought that people would move away from me. I stayed in a close community where if you needed something people would help. I wanted the people to move away from me. I would wear these big, ugly dresses like maternity style, a style I would never normally wear, *never*! They would come down to the ground with these big bulky jumpers. That was stuff I would never be seen wearing. I don't know if it was to signify that I was dead because I was told I was going to die? These were clothes that I would never have been seen in when I was

Diane's desire to purge herself of the virus manifested in a suicide attempt as well as a deliberate and sustained effort at inflicting pain upon herself.

Diane deliberately cultivated an unattractive appearance in the hope of remaining inconspicuous. Vulnerable, and fearful of exposure, Diane wished to distance herself from others.

alive.

67)I hated every man that I saw. I thought that all men had it. Any man that I looked at I believed that they had it. It took a long time to realise they didn't. I believed that men were the carriers. You see I had placed it with prostitutes - all women. Now if all these women get it, where on earth did they get it from? They got it from a man. It took along time for my new husband to come near me too.

68)When me and my husband had sex I would scrub myself afterwards and I would beg him to scrub himself. I'd make him. I had this intense fear of giving it to him. I've still got that fear. I'll always be petrified of giving it to him.

You said that even the medical profession had that mind set, that good people don't get it. How did that make you feel?

69)I think it made it easier because I didn't feel so stupid. Someone was as stupid as me. Later I thought that he should have known these things. How many other patients does he tell the same thing to? He was more or less telling me that I didn't deserve it.

Diane felt a deep hatred toward all men and imagined they were the carriers of HIV.

Diane will always be fearful of infecting an intimate other with HIV.

Diane felt the medical profession shared her ignorance concerning HIV. They perpetuated the notion that individuals of good moral standing and virtue don't contract AIDS.

In one way you felt you deserved it and in another you felt you didn't?

70) I don't know how to explain it. There are all these emotions at once. Sometimes I feel guilty that I've got it. The next minute it's a blessing in disguise. It has allowed me to go out and teach and I'm aware of AIDS. It's made me do what I wanted to do. My dream has come true. It's as though I contradict myself the whole time. One minute I'm happy about it and the next ... Once I thought I was mad. How could I feel good about getting it and then bad? How could I feel guilty all at once? I didn't know a person could have so many emotions all at once until now.

So you feel that in a way having HIV/AIDS has given you opportunities to do things you might not have?

71) Oh yes. I mean as I've said, I've achieved my dream of teaching other people. It's given me the opportunity to do that. I am so much more aware of people and happy to help them. It's as if I'm closer to the things that are important to me and I know what I want to do.

Diane experiences a host of both positive and negative emotions. She feels having HIV has presented both an opportunity and crisis.

For Diane, HIV has provided an opportunity to fulfill her dream of teaching others. She is imbued with a sense of direction and meaning in life.

You said you judged the whole society as rejection.

72) When the first people turned against me and I felt punished, I thought the whole society would reject and punish me. It made me withdraw and it made me not go out anymore. I just stayed in my own house with my family. I just went out for the basic things that I needed. If I didn't go out I wouldn't be subjected to the rejection again and the hurt. They didn't look at me when I was at home. I felt everybody knew. When I walked down the street somebody just looks at me - maybe they were looking at me because I had a nice dress - but I felt they all know I've got it. That's the first thing that comes into my mind - they all know. Everybody was looking at me and they were saying, "That's the lady with AIDS".

73) It's not as bad now because I've got to the point where I don't really care who knows. If I can get my message across that's fine. I don't care what they say about me but they mustn't attack my daughter. I realised that not everybody turns away from me when they hear the word AIDS. I've learnt that it's fear that turns people away because

Diane's initial experience of familial rejection shaped the way she proceeded to relate to others. She labelled her community as condemners and judges of sin, and responded to others in a paranoid and suspicious manner. In effect, Diane withdrew. At home she felt invisible and protected from hurt, humiliation and rejection. Outside she felt exposed, vulnerable and defenceless.

Diane is no longer so sensitive to discrimination because she understands the fear and ignorance underlying it.

they don't know what to do or say. I didn't know that then. I just thought it was because I had AIDS and they didn't want to come near me.

When you believed the virus was a punishment, how did that affect the way you lived with having HIV?

74) The virus was in my body and it was all over me. I would scratch it so I would literally make a sore. Then I could believe - well I know the virus is there because it's here. I would pinch myself and make these ugly blue marks. Maybe it was a reminder.

75) The first time my glands swelled up terribly then I wanted it to go away and I'd push it all the time. Maybe if I pushed it, it would move down so nobody would see. I felt that everybody could see these lumps. They felt big. I wanted to push them down and hide them. Now suddenly I wanted to hide it. If I got an infection like thrush or flu, I wouldn't go to the doctor and I wouldn't tell a friend. After being diagnosed I wouldn't tell anyone because I thought they'd think - that's AIDS! I suppose because I thought that everybody else does. It was like a secret and it weighed very deep

Diane felt contaminated with HIV. She would deliberately inflict pain on her body so as to remind herself of her affliction.

Fearful and ashamed of exposing her illness to others, Diane attempted to hide her physical manifestations of HIV. She felt that HIV was a secret which burdened her.

inside me.

You say you started going to support groups.

76) I was made very aware that I had AIDS from the moment I walked in the door. I didn't feel like a person anymore. I felt just like an AIDS victim. As far as they were concerned I wasn't a person, I wasn't Diane. They didn't want to know my name - they wanted to know my CD4 count. I didn't even know what that meant. They started talking about how last week I had this wrong with me. The whole time I was sitting there and I thought people would support me or say, "howz life?, are you feeling good?" They focused on the negative. I didn't know what to do. I sobbed my heart out the whole meeting. Everything that happens to them they blame on the virus. I don't.

77) The virus is a part of my life. It's just a small part of me. I've got a very big life, another side of me I do that's not AIDS. Even though I work with it all day when I get home I cut it off. The problems that I have at work stay there otherwise I can't survive.

Upon visiting a support group Diane felt more like a diseased object than a human being. She encountered negativity and felt distressed, unsupported and dehumanised.

Diane does not allow herself to be consumed by HIV.

Appendix C

Pat: Organization of data

Black male, aged 34 years

1)I was always sick - serious diarrhoea that wouldn't stop. I had headaches, night sweats and cramps. I used to take it very lightly because at that time I was a heavy drinker. I would tell myself that it was just a hangover and buy some more beers.

Pat attributed his various symptoms of HIV to alcoholism.

2)I was told by the doctor that I was HIV in September 1996 at Addington hospital. The doctor said, "Pat I would like to see you alone in a private room." Before he gave me the results he asked me about some places around SA because of my history. I related everything. After that he said I am going to give you some bad results. I asked him, "what bad results?" He said, "pertaining to AIDS." I said to him, "I am ready."

Pat was prepared for his diagnosis in a private setting where he was made to feel at ease.

3)At that time I was not aware of the difference between AIDS and HIV. I was ignorant. He said that I was HIV and that he didn't know how long I had been HIV. Then he said that it didn't mean it is the end of my life, that I was going to live for another fourteen years. So as I am talking to you now there are thirteen years left.

At the time of his diagnosis, Pat failed to distinguish between HIV and AIDS. The doctor assured Pat that he still had a future.

How did you feel at that moment?

4) Always when I get bad news I suppress emotions and depression. I looked at him and asked him what assistance he will be able to give me. He said that I will only come to the clinic to get some vitamin tablets because we don't have a cure for AIDS. And I looked at him and I walked out.

5) I went back to my flat. I used to stay with a woman there. I met this woman at a bar after my girlfriend had left me. In the evenings she would dress to kill and say that she was just going out to visit her friends. She would say that she'd see me tomorrow. It didn't bother me because I had many other girlfriends. She would always come back in the morning with money. I didn't suspect anything.

6) When I arrived at my flat she wasn't there. I relaxed. I went to the bar and had a few beers. I had no appetite. The following day the woman came. I didn't even inform her of the results. She asked me how I was and I said that I was recovering.

7) So I looked at my future being an HIV positive person. At that stage I didn't know

Whilst inquiring about possible aid, Pat concealed his feelings of depression. The doctor was honest with Pat and explained the appropriate procedure for receiving aid.

At the time of his diagnosis, Pat had a variety of girlfriends. He was also unsuspectingly engaged in a relationship with a prostitute.

Upon returning from the hospital, Pat proceeded to relax and failed to inform his girlfriend of his diagnosis.

Pat believed his death would be instantaneous and thus could not imagine a

about HIV the virus. I just looked at my situation and said I am going to die because I have seen people - when I was in the African states with the ANC- in the camps dying because of AIDS. I had that picture. I thought I was going to die then.

8) I said to myself that it is better if I take a serious decision. Firstly, I analysed my status and my whole life. My whole life came before me. I said that when I was living with my previous girlfriend I had no problems. This means that the person who infected me is this woman. I said I suspect it is her.

9) She used to drink wine and crown, so what I'm going to do is drug her. Also in the same flats as us were Nigerians selling mandrax. So I must buy a bottle of wine. I will buy about four tablets of mandrax or cocain and I will pour it into the bottle, mix it into the wine and give it to her as a present so that I drug her. After that I planned that I will throw her out of the window of my nine floor building. I wanted to murder her. I was so angry. Those were my plans.

10) I later decided not to do that. I felt it was unnecessary to kill her. It was my carelessness for not using condoms. I had

future as an HIV positive person. He equated HIV with AIDS and AIDS with a picture of people dying.

Pat proceeded to contemplate his existence. He acknowledged that he contracted HIV from the prostitute he had been living with.

Pat felt immense anger toward the woman who he believed infected him. His anger manifested in an intentional and premeditated plan to murder his prostitute girlfriend.

Pat decided to commit suicide after he accepted responsibility for contracting HIV.

slept with prostitutes and we'd used condoms. But with this woman we didn't so I felt it's better to kill myself instead.

11) My idea about AIDS was a person gets thin and thin with sores around his mouth and face and body. I didn't want to experience that. I also thought of other people with AIDS - it affects their brain. I just looked at that and I thought I don't want to suffer like that.

12) I thought of my children. My last born is two - I've got five children. I said that there is nothing I can do. I took a paper and a pen and I wrote all the reasons why I should commit suicide. I put the paper on the table.

13) I took my gun and I loaded two bullets. I felt that if one missed the second one would work. I was ready to die. I had that picture seeing people attending my funeral, seeing my body being removed from the flat. I was ready to kill myself. I took the gun, looked in the mirror, looked at myself. I thought of my background - where do I come from? I thought of my my past, my mother, brother and my father. I thought of all those things.

14) While I was still busy talking alone in

Pat's image of AIDS reflected the physical and mental suffering accompanying the disease. He decided he could not subject himself to such suffering.

Thinking of his children did not deter Pat from orchestrating his suicide plan. He rationalised why he should commit suicide.

Whilst Pat prepared to commit suicide, he conjured up a picture of his past, present and future.

Pat attributes the failure of his suicide

the room, my friend Mike just knocked and pushed the door. I would say maybe it was God. I forgot to lock the door and besides I didn't expect any visitors. It was nine o'clock in the morning. I always get visitors at lunch time. Mike found me sitting there with my nine mill gun and he asked what is happening. When I saw him I was demoralised and could not execute my suicide mission. Mike grabbed my gun and went to reception and called the manager who called the police. I was taken to the police station. At that time I couldn't speak. The first time I spoke was to the station commander. I told him my situation. He understood and was diplomatic. Then they took me to Addington hospital where I was committed for two weeks in the psychiatric ward.

15)After two weeks they decided to discharge me. The doctors and social workers said that because I am living alone in the flat they felt it necessary for me to go and stay in a place with many people where I could talk and relax. They chose the Ark - a Christian centre. They feared I was still going to commit suicide.

16)So I went to the Ark where I was welcomed with open arms. When I was at

attempt to divine intervention. After his friend interrupted him he felt demoralised. He was subsequently placed in a psychiatric ward.

Because his condition was still somewhat unstable, it was advised that Pat enter into the social environment of the Ark.

At the Ark Christian Centre, Pat felt welcomed and accepted. He proceeded to

the Ark they accepted me. I would go to the clinic and ask for medicine and I talked to the sister in charge. They let me go to the hospital to get medicine and the pastors prayed for me. I went to Open door and then a meeting at NAPWA and I met people and from there I was elected treasurer at NAPWA in Kwa-Zulu/Natal. I also like reading and am quick to learn so I started to learn about the difference between AIDS and HIV.

Did it help...to be introduced to others with HIV?

17) Meeting other people was wonderful. I thought to myself that it is very good to be with all these people like me with HIV. I felt better and I felt happy because everyone knew my condition. They also felt like me. It was good.

18)I thought to myself, it will be difficult to inform my family about this. I decided the best thing was to call the journalist and talk to the newspaper. I chose x magazine which is read by 3.5 million people. I felt that it would be nice for me to relate my story to the magazine. People would get my story from the magazine so that when I see them it won't be such a surprise and shock to them. I called the press and my story was

educate himself about HIV and AIDS and was introduced to a variety of people suffering from AIDS.

Pat encountered comfort, empathy and support upon meeting others with HIV. He felt that others understood him.

To avoid directly confronting intimate others, Pat decided to publicise his story to the media.

published.

How did your friends, family react?

19) Well recently I was at home and my step mother said to me, "I understand you've got this disease." She said, "You'll be fine." To them HIV is AIDS and at the same time AIDS to them is not a threat. People don't believe that AIDS is a killer disease so they take it very lightly. Many people, friends and women don't want to accept that I am HIV positive. The way I behave - I don't fit the HIV picture.

Are you in a relationship?

20) The last time I had sex was October 1996. Next month I will make it one year. It's not that I don't want to. The reason is that I would not like to see any one else go through what I am. At this stage I don't want to fall in love. My children are enough. I know that I can't have more children. I will never sleep with a woman without a condom, or impregnate her. I'm very sensitive to that. I keep my virus to me.

21) I'd like to highlight a point. HIV people are too attractive - they attract people. Men attract women. At this stage there are so many women who challenge me to propose to them. They don't know I am HIV

Pat's community's understanding of AIDS and HIV is characterised by disbelief and ignorance. They fail to distinguish between HIV and AIDS and cannot relate the disease to people.

Pat abstains from sexual intimacy in order to ensure that he does not infect others.

In Pat's experience, HIV is perceived as an excuse for not wanting to engage in relationships.

positive. If I tell them they will pass a remark like, “ you are scared of women”. I thank God that I am living in the Ark where there is a section for men and a section for women so I can control myself.

22)I just happened to have this HIV at the time when I had heard so many stories about it. When I was in exile for five years in the 1980's, we discussed AIDS. Through our political analysis and information from Russia (ANC was funded by communist countries and the west, America supported SA), we were told that AIDS originates from America. They put it very clear what happened. The scientists wanted to run business so they mixed some chemicals and then they wanted to experiment this in a human being. They payed a prisoner and the prisoner was infected with the chemical and the prisoner was released and slept with women. In Africa it came from the sea men who stopped at the harbours. That is the Russian side. I believed it because those were the people who gave us something to eat and dress and shelter. We just developed the hatred for the Americans. Then we read the other story from the Americans. They said AIDS came from Africa when African people ate green monkey.

Pat formulated an understanding of HIV prior to being diagnosed with the virus. His understanding of the origin of the virus was appropriated from political discourse. This discourse propagated a mythical and mysterious understanding of the disease - attributing AIDS to devious American, scientific endeavour.

23) I looked at the stories and I said to myself; If the scientists in America planned this thing in order to make money why can't they find a cure? That was how I felt. I also said that it is impossible that the scientists can just come with this thing that is killing the Americans themselves. I decided not to believe the story. That is when I decided that let God take all these problems of mine and work with him. Because I believe in God and I feel this is the work of the Devil.

Can you tell me more..

24) In the Ark we live spiritually, under the name of God. I decided to forget about this HIV, that it exists in my body.

25) You see I had a picture about a person who is HIV and I looked at myself and even the symptoms of HIV in my body were really frustrating me.

26) I felt like it was eating away at me so I concluded that it could be that the virus is something like an ant which is moving around in my body. That is one of the things that really tortured me.

27) Sometimes I could not sleep at night. I would lie on the bed during the day. I felt like it was eating away at me. I lost weight

Contemplating the stories relayed to him about AIDS, Pat felt disillusioned and decided to invest his faith in God. He identified AIDS as the work of the Devil.

Influenced by the spiritual atmosphere at the Ark, Pat decided to forget that HIV inhabited his body.

Pat's bodily symptoms were aggravated after conjuring up his image (see NMU11) of the physical disfigurement accompanying AIDS.

Pat imaginatively experienced HIV as an ant - an image which tormented him.

Plagued with this image, Pat felt as if he was being consumed by the virus. He encountered difficulty sleeping, lost a

to 50kgs. Everybody concluded that I was going to die. The pastors called me and prayed.

28) And then I said to myself; I am created by God and it's not possible that God can create me and at the very same time torture me like this. I would not say this is a punishment from God. I said this is Lucifer's thing. This is a demon from the Devil, from Satan.

29) So I said to myself; I am not HIV positive, the Devil is the one who's got HIV - not me.

30) Later I went to check my weight and it was 61kgs - magic! I had been talking to God, praying, and then there were miracles in my body. I had appetite.

So you talk to God?

31) Yes. The only thing is I pray to God. I say, "God please remove this demon from the Devil." This is my own perception.

Do you believe that God can take the demon out of you?

32) That was the reason for me going to the hospital to check my CD4's - whether that was God's work or not. I went for a blood

considerable amount of weight and was near death.

Pat felt so tormented that he decided Satan was responsible for creating HIV in the form of a demon.

Appropriating this attitude, Pat denied he was HIV positive - identifying HIV with the Devil instead.

Pat's physical condition began to improve after establishing and nourishing a relationship with God.

Pat appeals to God to remove HIV - the demon from the Devil - from his body.

Pat's belief in God's ability to remove HIV was affirmed by the doctor.

test to check my CD4 count and they discovered that God is really helping me. The results were marvellous. The doctor said, "It looks like HIV will very soon disappear from your body."

Do you believe it can?

33) The way I'm always talking and praying to God and open about my status - I feel that one day I will go and check and the results will be negative. It can be taken out of me.

Pat anticipates that HIV will eventually be removed from his body. This belief is strengthened through active communication with God.

34) The reason I say it's a demon from the Devil is that I know for a fact that God cannot create a person and give that person such a bad punishment.

To Pat HIV is synonymous with an evil punishment - something which Pat believes God is not capable of subjecting humanity to.

Do you see the virus as a punishment?

35) The virus is just something which comes from the Devil. It is not something that has been created by God or God's wishes. It's just the Devil's tactics.

Pat believes that HIV is the Devil's deadly game - having nothing to do with God. A firm polarity between good and evil is created.

36) I've accepted HIV. I know for a fact that it's the work of the Devil. I know for a fact that I am a sinner.

Pat is able to accept HIV because he is accepts that he is a sinner.

Sinner?

37) Because I've been involved in many things which God is opposed to. I make sure

Pat perceives himself as a sinner because he was engaged in activities which were

I don't blame God for being HIV. I just declare it as the work of the Devil - not of God. God has the power to remove this - it's not from him.

Does it help, seeing it like this?

38)It really helps me to cope with it. Because I'm open about my status, I talk about it and I forget it. Even when I walk in the streets I don't feel like a HIV positive person. I feel that I am now independent and free and liberated. I'm a free person. If you want to see me go to the hotels, the pool tables. I go to the park, play soccer, I socialise with everyone. My life is very nice and smooth. Life is normal. I do not allow the virus to command me, I'm controlling it 100%.

How?

39)Firstly, I avoid anger because I know for a fact that as soon as I get angry the virus gets more powerful. The anger automatically makes me worry. I don't hurt anyone. I like reading, not thinking too much. As soon as I think too much I will develop nerves and then the virus will get more powers. I also give myself enough time to relax.

40)I used to drink too much but now I tell myself I can look after my body and I can

contrary to God's law. He accepts this and invests his faith in God.

Pat describes himself as embracing and bodying forth a free and open attitude to the world.

Pat controls HIV by avoiding anger. When Pat feels angry he begins to feel anxious which in turn lowers his reserves.

Pat cares for his body and possess a positive mental attitude. He no longer indulges in

control my mind with positive thoughts. That is important. Most of the time you will find me sitting with my friends and I will order coffee or water. It doesn't bother me.

41)I cannot afford to buy medication. When I'm sitting alone I look at my situation and I think of Magic Johnson the wealthy basket ball player. It was so easy for him to get drugs to destroy that virus. If you are in the countries like America and you are rich and you suddenly discover that you are HIV positive, it is possible to get drugs and deal with it very quickly. I cannot afford to go for treatment that can fight the virus in my body. I just get those vitamins. In order for me to fight the virus I follow instructions from the doctor and I pray. I put God first. The only way I fight the virus is that I don't let the virus command me. I don't give the virus more powers. Myself I take the virus as a demon from the Devil so I survive by doing things contrary to what the Devil wants.

What does the demon look like?

42)When I look at the virus itself it is something like an ant. It goes in all the cells, moving all over my blood cells and eats me very slowly. Some cells it cannot eat. I also look at the picture where some of the cells

alcohol.

Unable to afford an effective treatment for HIV, Pat invests his faith in God and is guided by the doctor's advice. Pat lives according to the will of God.

Pat imaginatively perceives HIV an ant slowly devouring the life inside of him.

that I have in my body are already weak because I've damaged them by drinking etc. - so the virus gets more power. At the same time when I look at the picture of this ant, this thing which is moving within my body and cells, there are some parts in my body where it cannot go through because of the doctors instructions. In order to survive and be strong I do the doctors instructions and then the virus is powerless. That is how I picture it.

Is the demon male or female?

43) I picture it as bisexual because if it was a male then it would be sympathetic to men and destroy women. But it doesn't choose.

HIV is described as bisexual because it does not display a preference for men or women.

Clarificatory Interview.

You said that the "devil is the one who has HIV- not me".

44) The reason why I treat this HIV as a demon by the Devil is because I have stated very clearly that God cannot create people and at the same time give them such a terrible punishment, to die slowly. That is how I perceive the whole thing.

To Pat, HIV is synonymous with an evil punishment; a punishment which Pat believes God is incapable of inflicting upon human beings.

Like a torture?

45) Yes, because to have AIDS is a torture. I take it as a torture because you die very

Pat imaginatively perceives AIDS as punishment, a torture and death sentence.

slowly and at the very same time you live knowing for a fact that you are going to die. It is just like a death sentence but at the same time it is more than a death sentence because if it's a death sentence you know for a fact that you've been sentenced and that you are expecting to be hanged at a certain date and certain year. With HIV you don't know when you are going to die but you know for a fact that you are going to die. It is a serious punishment. That's why I always treat this as nothing but the work of the Devil.

So how does it feel - having a demon inside your body?

46)As I treat it as a demon in my body, I always emphasise that this body belongs to God and I always have to hope that God will not let the Devil destroy my body as I am a son of God. In my understanding, a human being and life is one of the most precious things that God has created so therefore wherever I go I always make sure that I forget that I have HIV.

47)I'd like to highlight a point. In the early stages of my having HIV there were some feelings that there was something that runs on my spine. I felt that it was a something that was untouchable because when I

HIV brings with it certainty of death but uncertainty regarding the exact time of death. Death is depicted as a slow and drawn out affair.

Pat invests his faith in God's power to protect him from the Devil's destructive intent. In order to concentrate on the life inside him, Pat forgets that HIV exists in his body. Pat's body is God's temple.

Pat initially imaginatively experienced HIV as an evasive, demonic ant inhabiting his body.

scratched my spine, I couldn't actually scratch it but there was certainly that feeling inside.

Like...

48) Like as if there was something moving on my spine, inside. I tried my best to scratch my body. It was not itching as such but irritating. This was with the sweats and the numbness. I concluded that it could be that the virus is something like an ant which is moving around my body. That is one of the things that really tortured me most of the time. This thing irritates and then when I respond by scratching my spine it becomes difficult to stop it because it becomes impossible for me to reach it.

So you couldn't control it?

49) Totally. But then what I would do when it started was just lie with my back and relax until it stops.

If the virus is evil what does it look like?

50) I see the virus as evil, something like a monster, or a Dracula, or a vampire, a real demon. Something which is always crazy for the blood of a human being. It wants to eat up the human being, a very greedy thing.

You also say that because it is not from

When Pat imagined the virus as an ant inhabiting his body. He felt tormented.

Pat felt he could not control the ant in his body.

Pat imaginatively perceives HIV as a diabolical force - personified as a vampire. This demon is relentless in its desire to consume human flesh.

God, that He can take it away?

51) Yes, God can take it away. The way I look at the whole situation, the way God can take it away is to supply more skills to the scientists and the doctors to get a cure to do away with this. Not that you just sleep and then automatically the following day you go to the hospital and have a blood test and the result is negative. But God will one day give power to the doctors and the scientists to get a cure.

52) There is nothing that can beat God. God can perform miracles. If you remember in the Bible, God saved people who had demons. God helped and prayed for those who were handicapped. God can perform miracles in my body.

53) The other thing I stress is that God says he can help those who help themselves. So myself as Pat, I make sure that I also help God by fighting the disease/virus through prayer and relaxation and the doctor's instructions. I don't just expect God to do miracles. It's a partnership. Me and God are working together to fight the virus. That's what is happening in my body. Myself and God, we cannot be defeated by this, that's what I'm always telling myself. Me and God fighting the enemy together, fighting the

Pat believes that God can eradicate HIV by providing science with the opportunity to discover a cure for AIDS.

Based upon his understanding of Biblical scripture, Pat perceives God as the ultimate saviour, capable of performing miracles in his body.

Pat and God participate in a mutual endeavour to conquer HIV's existence. Pat's body is akin to a landscape within which the fight between good and evil takes place.

Devil.

So that picture helps you to be strong?

54) To be strong yes, in order to conquer this demon. I never consulted any traditional healers because the traditional healers can only cure the symptoms not the AIDS. The traditional healers get powers from the ancestors. So when I pray I pray to God and I talk to the ancestors, my grandfather, grandmother, mother, to guide me and give me powers and remove the darkness in front of me. The darkness is called bad luck in African culture - when you cannot see a brighter future.

You say that the community takes AIDS lightly

55) People do not understand AIDS, they don't take it as a threat. They take it as something which does not affect black people, which only affects white people. It is a whiteman's disease. Most of the time when you talk about AIDS to them, you talk about something which has never existed in our society. They say it is from the white people not from the black people. When people die because of AIDS - if the funeral is conducted - the priest will never disclose that this person died of AIDS. It is a very big secret. The family will never

This imaginative perception helps Pat maintain his strength. Pat prays to God and his ancestors for guidance and strength.

Pat's community are ignorant of HIV/AIDS and perceive HIV/AIDS as a disease emanating from, and affecting Western society. HIV/AIDS is also preserved as a secret.

reveal to the community that the person has died of AIDS. The doctors will never tell the family that this person has passed away from AIDS. So now the family remains ignorant. These are their beliefs. This is what happens and it contributes to the ignorance. People fail to understand that people suffer from AIDS. It is not recognised.

You mention that your belief in God has helped you to cope with the virus?

56) My belief in God does help me because I would say presently, if I did not go to that place the Ark Christian centre, I would have died or I would have been spreading AIDS like hell.

57) I want to tell you an honest truth. There were some thoughts in my mind of developing a state of being a serial killer. Not killing women but infecting women like hell. It was the time when I was in hospital. I just developed this hatred for women because I thought it's only women. I'm not gay. I said that this came from women. I've never been involved in gay things. I felt like infecting all the women because of the anger.

Pat's belief in God proves an effective means of dealing with HIV.

Pat identified HIV/AIDS as a disease contracted from women. He felt that it could not be considered a homosexual disease because he was not of homosexual orientation nor had he ever participated in homosexual activities. Pat's anger manifested in a desire to infect all women.

You mentioned a feeling on the spine.

58) Something moved around. I would describe it as a demon in the form of an ant, moving around very slowly.

You also described the demon as a vampire/Dracula.

59) Yes. To me it looks like a blood thirsty vampire. When a person has AIDS they get very thin, all skin and bone. When you look at that person they look as though the blood has been drained from them. A person who has been slowly, slowly drained by a blood thirsty vampire.

Earlier you said that you wanted to infect all women.

60) I wanted to infect all women or take my axe and kill all of them. Yes, take a spear and cut off their heads. I just hated women. I wanted them to die.

61) I thought; I'm the one with this judgement passed on me, this sentence given to me to die very slowly. This I have acquired from a human being - a woman. I saw them as evil. Women, they are weaker than men. The devil plays on the sentiment of women. I felt that women are weak. They got it from the devil. The devil finds a woman a weaker person.

Pat imaginatively experienced HIV as a demonic ant inhabiting his body.

For Pat, the physical wasting accompanying AIDS makes it look as if the human being has been consumed by a greedy vampire.

Pat's hatred of women manifested in a desire to violently behead or axe them to death.

Pat imagined the virus as a judgement and a death sentence inflicted upon him by a woman. Pat believed women were the carriers of HIV because they were evil and susceptible to the Devil's temptations.

Do you still feel such hatred toward women?

62) Now I have learnt a lot about AIDS. That hatred towards women, it has vanished because now I know what AIDS is.

Pat's hatred toward women has disappeared since he is now educated about AIDS.

What do your ancestors think about AIDS?

63) This is a very difficult question. When at first people heard about AIDS they didn't know how to interpret it into Zulu. Until this man interpreted it into Zulu language, "Inculaza". When I sit down with old people they say that the disease has been here for a long time. A long time ago it wasn't called AIDS. But in those days people practised safer sex in a customary way. The woman was not allowed to have sex with a man out of ties. AIDS was just called a disease. But now we have lost our culture and tradition. The teenagers are no longer practising safe sex, they are just sleeping around.

According to the elders in Pat's community, AIDS has existed for a long time. The breaking down of cultural values and traditions, coupled with increasing promiscuity, is responsible for the sharp increase and prevalence of AIDS today.

You seem very involved in AIDS work...

64) Yes. I am very involved in AIDS work and it is marvellous because I have met so many people. Also, it gives me something to work for.

Through his involvement with AIDS work, Pat has been introduced to many people and received direction in his life.

Something to work for?

65) To take away this terrible stigma - yes.

Pat feels motivated to educate others and

There are a lot of people who don't know about this disease - especially in my community and community's all over. My job is to educate these people and fight for rights. I sometimes thank God I have been given this opportunity to educate others and be of use. Its better than before.

fight the stigma marking HIV/AIDS. Having HIV has provided Pat with a meaningful opportunity to do so.

Appendix D

Jan: Original protocol

White male, aged 71 years

1) I was diagnosed in 1994 but I must have been infected around about 1990. Before Christmas 1993, I was asked by the blood transfusion service to go to the clinic to have my blood tested. That was already an indication that there was something wrong. I went to the Blood Transfusion Centre and the woman who took blood samples put gloves on to feel if my glands were swollen, an indication of a very low immune system. I had no suspicion whatsoever. I have a girlfriend who also gives blood and in November she had to give blood and she wasn't told to come back. So I thought, why should they ask me and not her? Anyway I was diagnosed HIV.

How did you feel then?

2) A little shocked, not very. I had been partly prepared for it. A month before when they asked me to come in before Christmas, I didn't have time. So it was only in January that I went to the Blood Transfusion Service.

3) My main concern was about this woman. I phoned her there and then and she had a blood test and she was negative. I was prepared for death. Earlier on in 1993 I was diagnosed with prostate cancer. I was then ready to face death. I've been with the image of death for a long time so it wasn't a big shock.

4) I've been divorced from my wife for fifteen years. I picked up the virus in Botswana. I lived there for ten years. How I don't know. I don't think it was sexually because I had two women in Botswana and I contacted them and they were both negative. I think I was infected by blood being taken at a small clinic for AIDS and STD testing. I really don't know. I have no idea.

5) After I was diagnosed I went on a long vacation in the Far East for a family reunion. I told my brother and his wife and they were very sympathetic. I went backpacking and was away for nine months. I worked in an AIDS hospital in Thailand and did a lot of meditation. I learnt that it was

not so much the virus but the immune system which can be affected by meditation

Yes?

6)I visualise the immune system, or the virus, or the cancer. I do meditation to keep the cancer down and the immune system up. When I read this book (x), then I started to visualise this virus - the actual virus.

What do you see?

7)It's this virus that sort of flows through my body. Scientifically, the virus uses the cells, its own DNA, to split up into smaller pieces. It then leaves the cell and goes into another cell. The cell then breaks up. The visualisation is to make the CD4 cells stronger to stop the entry of the virus. That is what I visualise.

At the time of your diagnosis, did you have a picture of HIV/AIDS?

8)I had no picture whatsoever. I'd never thought of HIV/AIDS. I had no image. I knew that the immune system would be affected. The woman who tested me said I must watch my immune system. That was the only note she gave me. At present I think mainly about the immune system and not about anything else. I have to watch my immune system continuously. I'm continuously aware of what actually happens to my body. A little ache or pain I think; Could this be it, is this the beginning of it? But one can get so obsessive. I am very relaxed about it.

So...

9)I don't relate to my virus as such. I watch my immune system because that is more concrete than the nebulous concept of the virus. I focus on the immune system. The virus is sort of part and parcel of the immune system. The virus is a thing which affects, or may destroy, or may do something to the immune system. The immune system is something that I can control. The immune system is something that I know. I've got the African strain of the virus, dysentery, a gullet fungi infection. These are the things I get, they are indicators that the immune system is down.

So you work to keep your immune system up?

10) Yes. My energy meridians are affected by the virus. But the virus is a very nebulous concept. Scientifically, the virus is very random. It enters my body and enters the cells. It concentrates on the CD4 cells. There are other cells which it doesn't affect. Where does it enter? Where does it start multiplying in my body? I don't know because my blood just takes it. So in effect, it is in my blood stream and in the meridians in my body. The virus is in my blood.

11) You see you don't die of AIDS. AIDS doesn't exist as such. You die of pneumonia, dysentery, all sorts of things. The cause is that the virus has broken down the immune system to such an extent that there's nothing left. I don't see HIV as a concrete thing. I know that if I die the virus also dies. I don't know yet how to communicate with the virus. Indirectly I suppose I do when I do my meditation.

Can you describe to me what happens?

12) I visualise my blood flowing through my body, being cleansed by the air or the breathing, the spirit, the energy spirit from outside in our cosmos getting into my lungs, mixing with the blood, cleansing it, automatically picking up maybe the virus and when I breathe out, that goes out.

13) Another meditation I do is with light. I visualise I am breathing. I breathe in light that mixes up in my body and in my blood and when I breathe out, the grey light I visualise going out, going back to the sun to be cleansed there. So the sun and the cosmos is the filter, cleanser for my virus, for my blood, my meridians and energy lines.

So do you feel you communicate with your virus then?

14) Correct, but not really consciously that I think of the virus as little micros crawling around or as a personified person.

15) One's mind set is important. My mind used to think of the virus as evil. One minute before diagnosis I was a normal person, part of the community, a happy man. The next minute I

imagine myself to be a sinner. I did have a feeling of sin.

Can you tell me more about this?

16) Well, in my circle of friends and society, the concept is sexual. It is sexually transmitted with prostitutes. That was my concept as well so when I was diagnosed I didn't want to say anything about it because of the sinful concept. I felt like a sinner.

You didn't say anything?

17) Well no because of the sinful concept. I was afraid people would think bad things of me and I myself felt like a sinner.

18) You see today, this is what I am fighting against. People think it's evil. People believe that if you have AIDS you are evil, that you have done something wrong. When I had eventually come to the point where I put my trust in God, I no longer felt like a sinner. I didn't consider it as evil anymore.

So there came a point where you decided to invest your faith in God?

19) Yes. I turned to Him and let Him take all my concerns. After I was diagnosed my relationship with God was not good. I felt that he had abandoned me in a way. I suppose I was angry with him.

Angry?

20) I did have that feeling of anger towards God because I now had HIV. But that feeling left after I decided to place my belief in Him. Rather than getting caught up in anger and becoming bitter, I decided to turn to God. I felt that God could give me support and guidance, and He did. My faith in God is very important to me.

Did you feel rejected by others?

21) Yes there was certainly rejection. But like I said, it is because of the sinful concept and the

evil. People straight away thought I was evil because I had HIV.

Do you feel it's important to avoid seeing the virus as more than it is....

22)Yes. When you have flu, that's also a virus, no one worries. It's because the AIDS virus is such a mysterious thing. It's a mystery.

Do you see it like that?

23)Yes. I can't see it. Science can't see it either. I've been reading a lot of scientific books on the virus.

Does this help you?

24)Tremendously. Not only the technical aspect of the virus but also around the virus, the sin, the evil. Why does God do this to me? To come to terms with that, the spiritual. I'm a spiritual being. I'm always interested in the spiritual side of life.

Yet you seem to have quite a scientific approach to living with the virus?

25)Yes. If I want to become familiar with what I've got, I must know what actually happens. I must know the facts. It's no use having a nebulous idea. That's the problem with mediation. If I imagine the air or the sun to cleanse the grey matter which comes out of me, that's not scientific. There's a dualism in it. On the one hand, I want to know what is scientific. But I also want to know what is spirit. Scientifically, it's difficult to explain the spiritual. As far as I can see things scientifically that is what I would like to accept. Where science stops and where the spiritual takes over, I accept that too.

Living with your illness, which do you feel closer too?

26)More the spiritual side. Science explains what is happening in my body. The spiritual side helps the emotions because the emotions get buggered up.

Since you've had HIV, do you feel differently about your body...

27) This is not a representative situation because I've got this cancer of the prostate so they give me female hormones which change me. By reducing the male hormone output in the body, by overpowering it with the female hormones, there is a chance that the testosterone stops. I'm actually pharmaceutically castrated. That affects my mental attitude. I've become more feminine. For the past three years of my life I'm going through a different mental set up. My brain is different, it is wired slightly differently from the normal male aggressiveness to a more female pattern. I now approach life differently.

Can you tell me how?

28) I listen. The communication is now different. In the past I talked more, more aggressive, not as observant. I can't tell what the set up in my body is because my mind has been changed into a more feminine mind. The virus is also going through chakra centres, hormones, glands and so it may be that the virus is being directed into different streams. I don't know. Scientifically, I can't look at my body as a scientific object for just plain HIV because there are other symptoms involved.

Are you saying you don't see your body as a scientific object?

29) No, not at all. It is a biological factory but again there are certain things that are the magic. Why should my cell count go up? That's magic. Not from the magicians point of view. Spiritual, it may be grace.

Is it important for you to have a positive mind?

30) Very much. To try and keep the immune system up and not fight. It's important to have this fight aspect out. I have to co-operate with it. I can't fight my immune system. I have to help it, I have to assist it. In every corner I have to say, this is to the benefit of my immune system. It's working together.

Is this achieved by living a healthy lifestyle?

31) Yes. By disclosing, talking to people. By helping out. I do administration and finances here at NAPWA. I'm the father figure in the AIDS field. And reading and relationships with people are important.

You mention that part of living positively is talking to people

32) After I was diagnosed I kept everything secret until 1995. There was a world conference in Cape Town with 600 HIV positive people from all over the world. It was interesting talking to them and it was then that I realised, look you're not the only one. Often we, PWA's think we are unique, that there are few people who experience the same thing. I thought, I must go and work for an AIDS organisation and go public. For a year and a half I had only talked to two people.

How did you feel, meeting other people with AIDS and HIV.

33) Well, I would think it was a big relief for me because I had been carrying a heavy burden. I realised that I wasn't the only one with HIV.

34) When I decided to tell my family, I spoke to my ex - wife first. When we were divorced she thought that I left her for another woman. That wasn't the case. She has always accused me of sexual things. When I was diagnosed with prostate cancer she said she thought this was a solution to my sexuality. When I told her I am HIV positive, she said that it would be the death of my sexuality. That was her reaction. It took my daughter a year to allow me to play with my grandchildren again.

35) However, when I became public, I released a very heavy burden from me. It was essential that I spoke to my nearest family. It's a catharsis.

36) Part of living positively is that I can talk to people. It's amazing how many people I met just being open with it. I'm more open to people. It's given me a new lease on life. I've always been

very active and worked hard but I had visualised my retirement as putting my feet up and watching TV, doing nothing. This is completely the contrary. It has made me more active, extend my working activities instead of retiring. But because of my immune system I do get tired so I have to watch it. I rest a lot. I have to listen to my body.

More carefully now?

37) Yes. But it's clouded because of my cancer. I've got cancer and HIV. I know it's there because I get tired. I don't know who the culprit is. Again I watch my immune system. I can take medication and drugs, so I can control it. That's how I cope with it.

Clarificatory Interview

How often do you do meditation?

38) Twice a day virtually every day

How do you feel afterwards?

39) Relaxed, nothing special. There are no direct results. I don't know whether it works or not but so far I'm quite happy with my physical condition.

You mentioned before that the virus was evil.

40) In the beginning it was going to kill me. That was the mind set I had. When I was diagnosed I thought that I was evil, that I am going to die tomorrow. That is the concept that I had, that the media and the community give you. I underwent a complete rewiring of the brain. One minute I was a normal man and the next minute I was a sinner, evil, going to contaminate my surroundings and I was going to die tomorrow.

You said you thought you were going to "die tomorrow"...

41) Well yes. I didn't exactly know that I might still live for a long time with HIV. Instead I immediately thought I was going to die because of the disease. My time became a worry because

I wasn't sure if this meant immediate suffering and death.

So did you confuse HIV and AIDS?

42) I wasn't certain that the two differed. I thought that AIDS was the same thing.

How did you feel at that stage?

43) Well I must say I felt very anxious when I thought of AIDS because of the suffering. Physically, it is a frightening disease. I did feel a degree of fear thinking about that.

So you felt fearful and anxious?

44) Yes, it did worry me. More so than the cancer because with AIDS there is that notable physical suffering.

You said the image of death has been with you for a while.

45) Yes. I won't say I was happy about it but I had come to terms with death, that I am dying. The dying aspect was of less importance to me. The evil, the sin, the why does God do this to me. These were my first impressions, reactions.

Did you feel that it was a punishment of some kind?

46) Well that God had abandoned me. The punishment - it's what society and the church tells you. That's what I felt but I'm just a product of my society. So that's the concept that I also had of an AIDS person. When I was diagnosed I took over that concept. It's mainly because of promiscuity, the sexual aspect. Our society doesn't know what to do with sexuality so automatically when you are an AIDS person you are a sinner because you have been promiscuous, had many partners.

Did that make it more difficult for you to cope and deal with actually having the virus?

47) Sure, it was a problem. But the next step was to sit down and say; I'm going to read books about it. Not factual books on AIDS but things like - what is the interpretation of the Bible?

What does the Bible say about lepers - because that is the same concept. They have to live outside the city walls. How does God treat them?, because they were in the same position as we are.

So you imagined the picture of leprosy as AIDS?

48) Yes, and I realised that God is not a punishing God. He does not want to hurt me deliberately.

So this helped you?

49) Well it certainly relieved my concerns of the sin and the evil. When I thought of God as a loving father then I knew I did not have to feel like a sinner and an outcast.

50) I also had a book, "When bad things happen to good people" by a Rabbi. How did he cope with the bad news of a child dying? That appealed to me very much. So it was not *why* does God do this to me but rather *when* these things happen how do I cope with it. I looked at things like the randomness of accidents - why does it happen to people? In the holocaust the Jews said, "Where is God?" and the answer often is, "God is suffering with you."

51) It took about a year for me to come to terms with the idea that I am HIV positive. I converted my doubts and things into meditation, what can I do, how can I cope with this. It didn't worry me.

52) Over the years I've thought of this. I don't think I got the virus sexually. For me the sex act, I wouldn't say is a holy act but it is a special act and so getting infected is a special occasion. Why do you get infected in a loving act? At the same time I don't think I was infected in a loving act. I think I was infected through the needle.

If you were infected in a loving act how would that change the way you see things?

53) Well then it is not an evil virus. It is a virus which is special. I have come to terms with the fact that I am not fighting the virus.

54)The virus is no longer a danger. I've never actually seen the virus as an evil concept. I interpreted what other people thought of *me* not of the virus. In the eyes of the other people I felt evil.

So the virus was never evil?

55)No, I've never given the virus an actual picture as such. My perception of myself was of what other people perceived me to be. It's like a mirror image of what other people think of me, perceive of my being. It need not be that way at all. I mean my son said, "But dad I don't see you like that at all, you're not an evil person."

You don't see the virus as...

56)As anything but what it is. Through reading I've got another concept/image, that the virus is a very powerful virus, a very powerful life force and I can't fight it. So I've got to co-operate with it. I'm trying to work out in my mind, my soul, spiritually. I want to go to Russia to see how the medical profession cope with that concept. Concepts change continually through reading.

You referred to your body as a biological factory.

57)It's a biological factory but at the same time it's a spiritual factory as well.

Did you ever feel like HIV was indeed the "death of your sexuality"?

58)That was my ex-wife's concept of me, that I am a sexual person. Theoretically I am because I've always liked and been interested in women. But to me it wasn't. I just said that it is her interpretation because of what I've done to her. It wasn't my interpretation. I've got this girlfriend who certainly doesn't show that there's anything dying in me sexually.

Appendix E
Mercy: Original Protocol
Black female, aged 27 years

1)When I was first diagnosed it was the most traumatic thing. At that stage I thought HIV and AIDS were the same thing so I immediately thought I was going to die. I was pregnant with my baby and I thought the baby is already dead. That was my first question to the sister - is my baby dead? I cried, everything came to mind. I thought I was going to die. I didn't know it started as a virus and goes on to be AIDS.

2)Having the HIV status was a trauma for me. I lost my family, my husband, my job. Everything happened at the same time. I had to work on myself very hard.

3)I was crying every day, it was very lonely. I couldn't share it. I could see myself in the outside world. I couldn't communicate with them. It was like there was a wall there, a big dark wall between me and those close to me, mainly my husband.

So you felt isolated?

4)Yes. It was hard because I felt I couldn't speak to anyone about this HIV.

5)It took me a long time before I learnt the difference between HIV and AIDS. I demanded to know what happened and what was going to happen. I was especially thinking of my child. That kept me going. I wanted to live for my children and I needed to find out how possible that would be. So I sat down and learnt all about it. I started educating myself about the virus, understanding it, because I always believe that you cannot fight something you do not know. I can fight something that I know and understand.

Tell me more..

6)You see in the beginning I didn't know what HIV was so I held on to the idea of dying and I wouldn't have coped. But understanding the difference between HIV and AIDS helped me a lot,

knowing there were advantages of living long with HIV. Of course it depends on how you do it as an individual. There are rules for achieving that, living long periods.

You say you wouldn't have coped ...?

7) Thinking about AIDS and dying horribly made me feel scared and that doesn't help. Once I knew that I could still live a long time I felt relieved because then there's hope.

Did you have a picture or image of HIV/AIDS before you were diagnosed?

8) No I don't think so. I didn't really think about it. But maybe I thought of death. I knew that when a person has AIDS they would die horribly.

You mention something about fighting HIV.

9) I did and I'm doing it even now.

Can you tell me a bit more about this?

10) I fight HIV mentally. You see it's a very special virus, it doesn't want to die. The only thing it does, it wants, is to live within me when I am alive. When I am dead it will die. So I don't believe it wants to die. It wants to live. I've got to keep up my mental status at the same level as the virus. Through mind power. It helps me a lot - all the literature I've read. I'm in a position now where I am very friendly with my virus. If I let the virus be in the same mind level with my mind it helps a lot. I don't fight with anger and depression. I fight in a more positive way, that I also want to live, not to kill the virus. I don't want to kill it.

Is it like living in harmony with your virus?

11) Yes that's exactly what I'm doing. Because if I hate my virus I might as well hate myself because it's within me. There's no way I can exclude myself from it.

Are you saying your virus is you?

12) Yes it's me. So if I hate it and fight against it with anger, I'm not going to defeat it very

easily. But if I fight against it, understanding it and learning more about it, it puts me in a position where I say, “what next.” So I limit myself from taking a lot of anti depressant medication and going to doctors. I don’t have to do that because it’s all in the mind. It limits me from getting sick, because I am not sick. I’ve got a virus but I’m not sick. The best way is for me to live with it because I’m healthy. By the time it reaches the stage where it’s also tired and its energy level is tired and it has penetrated in a way that there is nothing left for it, or useful for it in my body, then that is obviously when my immune system is completely finished and the virus wants nothing more in my body. It’s finished its job. It lets go of the situation and I’ll start getting sicker.

Do you ever picture the virus?

13) If I meditate I picture my virus. I have done that many times. I use some meditation tapes that are related to HIV. The first time I listened to it I was actually scared. I thought it was too hard for me. It took a lot of practise and guts to lie down alone in the house, switch off everything and take my mind completely out of the world.

Describe it to me.

14) I picture myself in a place where there’s nobody, where there’s no problems. There is only me and my virus. I picture me and the virus living in harmony where even people are pointing and saying things but that is not going to disturb me and my virus because I’ve got a long way to go with it. And I picture myself not seeing the importance of what the other person is saying but the importance of what my mind is saying to me. And if I agree with my mind I am not going to agree with what the next person is saying because the person in this country will most probably be saying all negative things because of lack of understanding. That is how I visualise the virus within me.

Is living each day the most important thing to do?

15) Exactly yes. I just take everything as it comes. One day at a time. I’m not looking for amazing and mysterious things. I am a simple person who sees life very simply and I face life the way it

is. I've never appreciated life like I do now. I was not looking at life as the most precious thing because I thought I had everything, I had a family. I'm the last child at home, I've got brothers, everyone is still alive. We've never seen death at home. The first death came with me and my family. Right now life is very precious. I look at it differently than I used to. More special and passion. I've always had passion and love for people, concerns for people who are hungry, who don't have clothes, kids in the streets. I feel that much more now.

So you feel that having HIV has enabled you to appreciate things more?

16)Yes. I have changed in the way that I appreciate life more than I ever did before. Relationships are also very important. Loving and caring for people is important to me. I feel that to be one of the most important things to me. It is more important to me than it was.

17)To be honest, maybe if I die because of other reasons, I'll die because of the love that I've got for people. I cannot stand to see people suffering, dying, hungry. Because I am working directly with the same thing I am infected with, obviously there are times when I cannot take it. One of the reasons why I went open about my status was because I don't want other women to go through what I go through.

Did going public help you?

18)Oh yes.

Can you tell me why?

19)It's a feeling of being accepted. Before I couldn't speak about it and it was lonely. After I spoke to people about this HIV I felt better because there were also a lot of other people that were suffering. It helps because then everyone talks and there is a feeling of being together. I had to go public otherwise I wouldn't have coped.

Does working with AIDS help you in some way cope with your virus?

20)Well there's a lot of politics in AIDS. A lot of stress. Especially when I am directly affected.

I see people dying and I ask myself questions like; What is going to happen to me tomorrow? So many people have died on my hands I've lost count.

But you do seem to be very active in AIDS work.

21) Yes because I see it as my duty to help others. I know what it feels like to have HIV. I know the ignorance out there and the terrible discrimination. If I can help other people it makes me feel good inside.

So you have a purpose?

22) Yes. I feel that I am being of use to others.

How do you feel about death?

23) It has become a normal thing to me. Although I cannot stop crying when it happens. I see someone I know die and I say to myself, "But that person was healthy and they just died." I start asking all the questions like; "When exactly is the terminally AIDS stage?" People just get sick today and three days later they are gone. I say to myself, "I want to live long with my virus, for fifteen years they say you can live. But where is the possibility when other people just die like flies?" But I always have my courage, my courage brings me back. I'm not the same as others. I might die another way.

24) I've unpacked and packed everything that doesn't belong to me anymore and thrown it somewhere else. I had a family, I had a baby. My family is finished because of AIDS. There are only two of us left now - me and my son. I had to pack all that and say that when people leave they leave to die. We are born as people and our end of the road is death - everybody. I had to take it in that manner and say, "They are gone, I can't go back. It's over."

25) But now I've got life in front of me with my son. That is what I have to face and challenge. I can't dwell on what happened because what happened cannot be brought back.

So you choose to look to the future?

26) I choose to look to the future because I don't know what the future holds for me. I'm not living in a lot of hope for a cure. I never talk about cures or pray to God for a cure. Once you wish something and it doesn't happen, it destroys you. Once I promise my heart that something somehow is going to happen and it doesn't happen, I'm back to square one, I haven't moved. I can't promise my heart something that might not happen. It's important for me as a person to live in the present day rather than thinking of the past or future.

27) I'm very health conscious, health is my first priority. I live a normal careful life that's all. The most important thing is not infecting other people and infecting myself. I am very selfish with my virus. I believe in keeping it to myself, not giving it to anybody else. Keeping it to myself will save me. Passing it on to others will not help me.

28) I just told myself I won't give up. Life goes on. I don't see the reason to give up. I am no different to other people. I always congratulate myself and motivate myself and say I am more healthy than other people. That motivates my self-esteem, keeps me up. If I look at most people, a lot of them are sick. People are dying everyday and they go through hardship. When I look at my situation I am much better, though emotionally sometimes I'm not. I always speak out and am always open about my feelings. That has helped me to deal with HIV. I became open about my status very quickly.

When you were first diagnosed you said you couldn't speak to people

29) Yes. That was terrible and lonely. I felt I couldn't speak about me having HIV because I was very confused and scared then.

How did having HIV affect your relationships with people?

30) A few years ago after I was diagnosed I was at the stage where I wanted nothing to do with men. I hated men. I felt betrayed. A man gave me the virus. I proved that with my husband. He was later diagnosed with HIV and died before me. I'm in a relationship now with a man that's

not HIV positive. It's just a normal relationship and we hardly talk about HIV unless it's necessary. We take all the precautions. Life carries on.

31) Now I'm very open with the newspapers, TV, whatever. If a guy proposes I always assume that they've seen me on television. When I say I am HIV they don't believe I can be so fat and HIV at the same time. They've got misconceptions that we are pulling away from men because we don't want relationships. We use HIV as an excuse. But I stick to my words.

32) People cannot relate HIV/AIDS to people out there. My husband went out and slept with a woman without knowing because she's clean, educated, driving a car. Nobody relates the HIV virus to anybody they come across.

Is there disbelief?

33) People isolate it from themselves. My husband did something that is normal to the whole world. He went out and slept with someone. The thing that was wrong is how he slept with that person. He didn't take precautions.

34) It hurts me to see the lack of understanding that we have to challenge as people with HIV. Some people with HIV also don't know that there are ways of living. Love is the most important cure. I always believe that love is the best cure that one can ever get, not only in a relationship but in a family environment. People still loving me for who I am, what I've got, how I look. To feel that love, it can keep me going. It's not something that we buy or work for. It's something that is there, it's nature. If we find love and really see the meaning of love then we see how important it is. To open up to families and seek love.

Do you love your virus?

35) I do, I do but I hate it. I love it but I hate it for taking away my child. As a mother it's very difficult to just let go. I know the cost and it hurts. Why was she not saved from that? I look at it as well and say there was a purpose. I always prayed to God and said I'm the first one that

found out about this mess, make me have the strength to look after them. If we are all going to die let them go first so I can bury them and feel that sense of responsibility towards what I brought home. I don't think I would have coped to leave my child knowing that she's going to die alone without me. I know she died peacefully with all the love she needed at that moment. I'm happy about that. I appreciate all the years with her. The memories will always keep me going. I don't hold those memories making them control me. I look at them and see what the good things are. I can take the good things out of these memories and walk with them. I am not bitter.

Is your relationship with God important to you?

36) It is very important for me to talk to God and feel cherished by Him. He is the one who looks after me and keeps me going.

You really live positively.

37) Yes and with nothing but just my mind. I don't want anything that doesn't make sense to me just to destroy me. My mind is very important. In the same way if I do something I've got to believe in it. My mind has so say this thing is helping me. If I use something and my mind is completely out of track it won't work. In our African Sotho saying we say that if you take medication and your mind doesn't believe in what you are taking it's not going to work. I believe that if medication is used with a mind that it not stable it is not going to work.

So you find that..

38) Maybe it's because of my beliefs, I don't know. I don't take much medication. When it's time for me, when I'm terminally ill, I'll be taking medication with a mind that I want to become well and because I haven't used medication for a time my immune is not used to them. By that time it will be much more effective to help me.

Have you ever pictured it any other way?

39) I think the picture is very nice in the way that it only wants a human body. A human being

is very nice. So it must be decent to want to live in a human's body. Why didn't he choose cats or other creatures in the world? Why did he particularly choose a human being? And especially the entry of it. He chose the most special entry, that was created, that is normal to us. Sex, sex is something that every human being and every creature does. When sex happens between human beings it's normally out of love, joy and happiness. It also makes its entry through blood. That is the most important thing, you can't live without your blood. In an accident you have to get blood. It's the most special in the world. So I can the virus is very unique. It's able as well to change its forms within the human body. Even scientists cannot come up with clear results how it happened. The way I'm sitting now, scientists will try and find something to attack it from that side- it changes, just like a human being. If I leave you in this room, you are happy and excited for your birthday. If I walk out and somebody else comes to make you upset and go out, if I come back you will be changed. So it's a very unique virus. That's how I see it. Maybe because I'm friendly with it. It's not my enemy. If I take it as my enemy then I will be my own enemy and how will I even look at myself in the mirror if I hate myself?

40)I would hate myself very much if every time I looked in the mirror I'd see HIV. I wouldn't see Mercy. I want to see Mercy I don't want to see HIV. Immediately when I see Mercy, I see HIV, but I must not put that in my mind because HIV is Mercy. I'm living with it so I cannot be separated from it. I cannot say I am just Mercy, my last statement would be ... "and I'm HIV positive." I cannot isolate myself from it. Maybe in the near future when I decide to leave AIDS work that will change. I don't think it will change in the sense that I see myself as Mercy. It would change because maybe I wouldn't have to work with AIDS everyday, talk about it everyday. So I'd know that I'm living with it but forget that.

