Mind, Body and Social Components in Disease Progression and Resistance: A Study of People Diagnosed as HIV Positive

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A dissertation submitted to the Faculty of Arts, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the Degree of Bachelor of Arts in Social Work.

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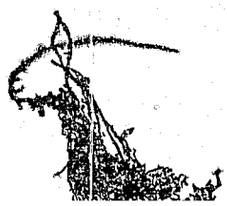
Declaration

I hereby declare that this dissertation is my own unaided work and that I have given full acknowledgement to the sources which I have used.

H I Katz

08/10/1999

Date



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My mother Leah - whose 'chicken soup' is the essence of her being.

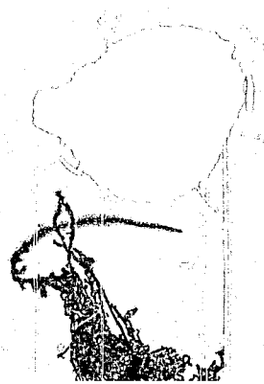
My father Lionel - my real confidante, whose character I mirror.

My mother-in-law Phyllis - who herself is struggling on a healing journey.

My father-in-law Arthur - whose capacity to cope despite the circumstances is inspiring.

My nephews Daniel and Aaron - I'm getting there guys, it's fishing time soon!

Julian - who rode this journey with me and continues to ride.



Abstract

This research aimed to create deeper insight into the coping experiences and meanings HIV positive respondents attach to healing and disease resistance.

This phenomenological study sought to generate knowledge grounded in real lived experiences. The three HIV positive participants involved, although differing in their duration of carrying this status, were asymptomatic and believed in the power of self healing. Through the medium of conversational discourse, data was gathered through a series of individual narrative interviews, focused by an interview guide. This promoted the exploration of the participants' subjective reality.

The findings suggest that carrying an HIV positive status may invoke a victim orientated response, upheld by societal discourse. Yet, this status need not be perceived or experienced as a death sentence. Rather it may become an opportunity to develop one's self and establish a sense of belonging with others and the world itself. These and other variables, seem to interactively generate a healing response at immunological, psychological and spiritual levels.

It is recommended that social workers and others involved in the realm of health care, adopt a strengths orientation to helping at individual, group and community levels. Through the social interactions inherent in these working relationships, disease progression may be hindered. Further, that intervention with the HIV positive client's extended systems be undertaken. Finally, that an environment conducive to healing be promoted through environmental intervention.

"Everything can be taken from a man but one thing - the last of the human freedoms - to choose one's attitude in any given set of circumstances, to choose one's own way"
(Frankel, cited in Hafen et al, 1996: 603).

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GLOSSARY

Asymptomatic: Within the HIV/AIDS hypothesis, this is defined as a stage when HIV is trapped in the lymph nodes. As the immune system produces two powerful defence mechanisms: antibodies that neutralise HIV particles in the blood and Natural Killer cells that attack and destroy infected tissue, no symptoms of HIV occur. This stage can last a decade or more (Wulf, 1996).

Biopsychosocial Perspective: This suggests that health is the outcome of a number of factors interacting together (Collinge, 1996).

Constructivism: This denotes that human beings have a mediated and not a direct knowledge of the world. Their knowledge of the world is dependent on the lens through which the observation is made. This promotes notions of individual meaning systems (Saari, 1991).

Emic Perspective/ Empowerment: A process that involves increasing personal, interpersonal and political power, so that individuals and collectives can take action to improve their life situations (Guiterrez, cited in Kromberg, 1990 : 13).

Epistemology: This refers to the relationship between the 'knower' and the known, the researcher and reality. It is this relational assumption, dependent on the ontological premise, that determines the process of research (Eisner and Peshkin, 1990).

Etic Perspective/ First order constructs: "Attempts to understand practices and behaviours within the context in which they occur. It attempts empathically to enter the frame of the other and to understand the meaning and significance of behaviours within the groups in which they occur" (Straker cited in McKendrick and Hoffman, 1990: 171).

Grounded Theory: Theory derived from real life data and not theory logically deduced about human events. It is considered 'bottom up' theory, built from lived experience as opposed to 'top down' theory based on apriori abstractions

about life experience (Goldstein, 1991: 104). It is developed via a process of construction in which second order constructs are developed to understand the first order constructs of the actors in the social world (Woods, 1995)

Immune System: A complex and multifaceted biological system, that functions to recognise and destroy invading pathogens and neoplastically transformed cells, while leaving the bodies of normal cells called 'self', intact (Miller, 1998).

Methodology: This refers to the methods used to obtain knowledge and is largely dependent on the ontological and epistemological assumptions (Eisner and Peshkin, 1990; De Vos, 1998).

Natural Attitude: "The unquestioned definition (either individually held or intersubjectively shared) of aspects of the world as they appear to the person" (Goldstein, 1991:105).

Neuropeptides: Chemicals triggered by emotion are thoughts converted into matter. In this way, emotions lie physically in our bodies interacting with cells and tissues (Pert, cited in Health Independent, 1999).

Ontology: This refers to the assumptions about the nature of reality and human behaviour, i.e. what is 'knowable' (Eisner and Peshkin, 1990; De Vos, 1998).

Phenomenology: This viewpoint advocates the study of direct experience taken at face value. It sees behaviour as determined by the phenomenon of experience, rather than by external, objective and physically described realities. Thus, it refers to the desire to get as close to the research as possible, where the findings of research are the product of the subjective mind (Cohen and Manion, 1994; Woods, 1995).

Psychoneuroimmunology (PNI): PNI is concerned with the nature and ramifications of central nervous system and immune system interactions, including mechanisms underlying psychosocial factors in the onset and course of immunologically resisted and mediated diseases (Ader, 1991).

Reactivity:	In line with the ontological and epistemological assumptions, the researcher is considered a component within the field of study. Thus, reciprocity occurs between the researcher and the respondent (Lincoln, 1995).
Relaxation:	A physiological process and quietening down of the mind, in which energy is conserved and a balance of energy maintained (Kaiser, 1993).
Second order constructs:	"The perception and evaluation of the practices of one group by another... It is a problematic perspective as it evaluates practices and behaviours from the outside, often without due regard to the context in which they occur" (Straker cited in McKendrick and Hoffman, 1990: 171).
Self:	On one hand it is defined as the person's attitudes and feelings about himself, and on the other, it is regarded as a group of psychological processes which govern behaviour (Gunter and Yeakel, 1980).
Social Development:	"A process of planned social change designed to promote people's welfare in conjunction with a comprehensive process of economic development" (Midgley, cited in White Paper for Social Welfare, 1997: 96).
Stress	This is defined as a subjective mental state that is not characteristic of the environment nor individual, but is a product of how one appraises and responds to one's environment. Thus it is a disturbance that occurs at external and mental levels with a corresponding physiological response (Martin, 1997).
Subjectivity:	That which distinguishes human consciousness from the material and social world. Consciousness refers to an individual's psychological state, in part defined by multiple power relations and conflicting interests of class, race and sexual orientation (Eisner and Peshkin, 1990).
T cell count:	A means of monitoring the immune system functioning. The number of T cells or CD4 cells indicate the strength of the immune system. A normal count falls between 600 to 1200 per mm (Centre for Disease Control and Prevention, 1999).

Viral Load: The measurement of the amount of HIV in the blood, in a millilitre of plasma. Tests are sensitive to a viral load minimum of 50. Any less is defined as undetectable, which does not necessarily mean there is no HIV in the blood (Catie, 1999).

CHAPTER 1

INTRODUCTION

1.1 MOTIVATION FOR THE STUDY

My quest to understand how people experience the mind, body and social components as an inseparable alliance within 'disease management and prevention', began as I was told incredible stories of people who had overcome their doctor's grim prognosis: *"..She walked into my rooms and told me her doctor had said I was to prepare her for her death..she was twenty nine with three weeks to live..ten years later she was married with children"* (Weinberg, face to face interview, 1998).

My intrigue sits as a microcosm within current socio-political and economic trends. An overarching theme of *connectedness* is reflected in South Africa's (SA) new democratic dispensation, traditional African philosophies of holism, and in the globalisation process. These socio-economic and political processes have direct bearing on the well-being of the individual, family and community. Hence, I embraced the holistic thought of the eco-systemic paradigm which reflects a shift from Western dualism, that locates needs and problems within the person, to a systemic view of human beings in constant interchange with all levels of their environment. This interactional field impacts on the biological, cognitive, emotional and social functioning of the human being (Germain, 1980). I recognised that health care and the process of healing reflects a complexity of interdependent systems.

I learnt that South Africa has one of the fastest growing HIV epidemics in the world. With a 22% infection rate, the disease has spun out of control. "Barring a *medical miracle*, 1 in every 5 adults will die within the next decade", dropping life expectancy to below 40 years by 2010. This social tragedy translates into an economic disaster (Halweil and Brown 1999: 1).

Moreover, The White Paper for Social Welfare (1997) is moulded on the discourse of intersectoral collaboration, yet responsibility for AIDS care lies with the Department of Health. AIDS co-ordinators have little power in policy processes, and implementation is incoherent (Schneider, 1998). Due to the impact of HIV, SA's economic growth has decreased by 1% annually, rendering financial means to health care a casualty in itself (AIDS Consortium, 1999). Despite a South African constitution lodged in equality, most private medical aid schemes exclude the treatment of HIV and AIDS. As macro-economic policies emphasise fiscal discipline, social spending in SA has failed to increase. Until recently, affordability of HIV treatment in SA was obstructed, as the United States hindered SA from obtaining lower prices for pharmaceuticals. In a context of global and local inequity, sustainable access to health care services is inhibited and people are dying of AIDS without dignity. Health issues are innately linked to superpower politics and human rights (Treatment and Action Campaign, 1999).

As I read Schneider's (1998) debate that AIDS in SA symbolises the need to extract public accountability, it became apparent that society externalises responsibility to the health sector. Embedded in a context of inadequate health care, the search for alternatives is infused with a new energy (Rankin, 1997). Saleeby (1996) argues that one cannot deny real concerns, yet objects to the denial of possibilities and hope. This view recognises the power of the self to heal, with the help of the environment. Hence, this paper explores the notion of reclaiming personal power. Healing is reviewed in transactional terms and the light shines on the interaction of inner healing capacities and processes of intrapersonal competency (Whittaker & Tracy, 1987; Kromberg et al, 1992). This perspective compliments SA's macro framework, as The New South African Medicines and Medical Devices Regulatory Authority Act, gives equal status to complementary forms of healing (Hepner, 1998).

The debate regarding health and illness, in the realm of social work, is cardinal. The social functioning of clients is not detached from their physical domain. HIV and AIDS disrupts their occupation, economic stability, family life and overall functioning. As a mind-body interconnection is superimposed on the eco-systemic transactions in healing, so the systemic relatedness of all entities is deepened. Moreover, *individuals* who impact on *their* immunity and sense of personal control, may ripple such effects within familial and community contexts (Sewpaul, 1995; Miller, 1997). Following this, I chose to inquire about the experiences of those who believe they have managed to change the course of their HIV status and understand how their healing process reflects the interaction of the mind, body and social constituents.

1.2 INITIAL ASSUMPTIONS

1.2.1 To perceive HIV and healing as a linear process of cause and effect was too simplistic.

1.2.2 To focus on the negatives of HIV, that engulf our media, was insufficient and detrimental.

1.2.3 The mind-body connection should be incorporated into social work thought.

1.2.4 The attitudes, behaviour and narratives of one person would influence those of another. Thus healing was assumed to be a potentially systemic issue.

1.2.5 The process of receiving social support was a passive one and vital within the healing process.

1.2.6 Macro and micro level entities are in reciprocal interaction. Thus social workers need to involve themselves at both levels.

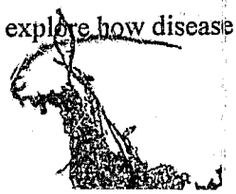
1.3 AIMS OF THE STUDY

1.3.1 The broad aim of this study is to generate a deepened understanding of the meanings and coping experiences that the HIV positive respondents attach to disease resistance and healing.

1.3.2 To understand how beliefs in the power of self healing influence the management of HIV.

1.3.3 To discover what factors are thought to be involved in self empowered healing and disease resistance.

1.3.4 To explore how disease resistant behaviour impacts on the social functioning of the individual.



1.3.5 To explore how disease resistant behaviour impacts on the individual's social environment, family and community.

1.3.6 To identify gaps in our biomedical understanding of healing and develop a more holistic and empowering perception of health and disease, thereby informing social work practice.

1.4 VALUE OF STUDY

By developing an in-depth comprehension of the meanings attached to circular interactions in health and disease, it is my hope that social workers and others in health related fields may utilise this knowledge to transcend a powerless observation of the negative impact of HIV and AIDS. They may adopt a critical perspective towards mainstream thought and assist devalued groups through an empowerment orientation. I realise this study is a seed in the cycle of such an inquiry, yet, in linking theory and practice, this research may impact on the following developmental concepts (Gray, 1997):

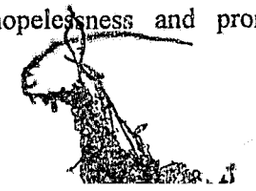
Prevention: communities may be conscientised regarding health maintenance factors; *Empowerment:* clients may actively participate in their *own* healing process; *Social development:* disease resistant behaviour permits economic productivity, potentially interrupting the cycle of poverty which supports this vulnerability; *Sustainability:* self-reliance in healing creates opportunities for sustained improvement in peoples' current health and their position to facilitate wellness in present and future generations; *Appropriateness:* 'health' may become located in African philosophy of holism, indigenising the helping and healing process (Sewpaul, 1995; Woods, 1998; Heywood, 1998).

Disciplines in health related fields may begin to shift health care delivery from a biomedical perspective towards a biopsychosocial model, based on a systems approach. Thus, multidisciplinary collaboration, which facilitates social development, may be promoted (Van Hook and Ford, 1999).

Health workers may recognise how meaning manifests in narrative, influencing feelings and action. As professional understanding becomes grounded in personal narrative, so the client may be assisted to recreate scenarios of possibility, in which the focus shifts from problem to solution (Saleeby, 1994).

In voicing the stories of three HIV positive people, this study discloses that which was silenced, links the respondent to a larger world, allows for the experience of a cohesive self and gives strength to the group. In some small way, this may promote a culture of participatory democracy (Saleeby, 1994).

In considering qualitative research a community project that connects individual constructions and the larger environment, it is my hope that these stories and findings are transferred to individuals, families and communities suffering the effects of HIV and AIDS (Lincoln, 1995). Perhaps in learning of the respondents' subjective experiences, others may respect and foster individual and collective agency, shifting hopelessness and promoting prevention and treatment. Thus, this study may elicit



complementary social work values of individuation and collective participation. "The self grows not from 'inner' essence relatively independent of the social world, but from experiences in a world of meanings, images and social bonds.." (Rosaldo, cited in Saleeby, 1994: 352).

In the journey of discovery, the cycle of inquiry is never complete. Perhaps this project may spark off further research and continue a process of empowerment, as we critique dominant perspectives and give voice to alternative versions of the world (Durrheim, 1997). It is my hope that the theory of practice begins to reflect individual constructions, allowing this study to inform not only our thoughts, but our practice intervention (Saleeby, 1994; Fook, 1996).

1.5 RESEARCH DESIGN AND METHODOLOGY

The research used is based on qualitative methodology, using a narrative design. The narrative, engulfed in human meanings, allows one to get as close to the research as possible. This counters empiricist thought that renders the mind as passive and knowledge as a mirror of nature (Durrheim, 1997). Rather the assumption underpinning this study, reflects the belief that reality is a construct. Hence, conversational discourse, focused by an interview guide, propelled the discovery of subjective meaning (Goldstein, 1991). In placing primacy on subjectivity, the respondents creatively authored their stories, bringing new knowledge about disease resistance and progression. Although this may have generated grounded theory, a dialectic emerged, as I analysed the data with ideas and ideas were shaped by the data I analysed. Thus the study became a search for themes, patterns and the meanings respondents attributed towards them (Riessman, 1993; Dey, 1993).

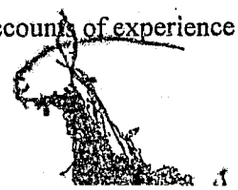
Qualitative methodology is described as a journey, its conclusion reached only by travelling it. It is a product embedded in a process, in which paradoxical approaches of condensation and synthesis, induction and deduction, singularities and generalisations, rigour and creativity work together in mutual enhancement: "We think in generalities, we live in detail" (Whitehead, cited in Dey, 1993: 94).

1.6 LIMITATIONS

1.6.1 The availability of information on HIV and AIDS is immense and undergoing continuous change. This study is of limited scope, inhibiting an extensive coverage. Thus I have concentrated my focus on current information that covers immunological and sociological components of the illness.

1.6.2 The time span of this study created limitations to the scope of the literature search, number of respondents and interviews involved. Thus, data gathering and analysis were bound in time.

1.6.3 A lack of literature regarding the impact of mind-body healing with specific regard to HIV and AIDS restricts the etic perspective hereof. However, it does promote an inductive stance, as the "first person's accounts of experience are used as a primary source of information" (Riessman, 1993:54).



CHAPTER 2

HIV AND AIDS: DISEASE RESISTANCE AND HEALTH ENHANCEMENT

2.1 INTRODUCTION

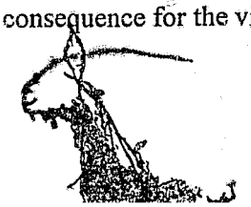
For some the diagnosis of a serious illness is perceived as the final blow, as they resign to the belief of powerlessness. Others define their disease as a gift, a challenge.. they don't take it as a sentence.. but perceive it as an opportunity to live.. to travel the journey within (Hafen et al, 1996; Bittman, 1999).

In order to explore the biopsychosocial context of health and diseas-e, this chapter reviews current literature around HIV and AIDS in a South African and global context. This body of knowledge focuses on the medical factors and obstacles faced by those with HIV. Little research reviews how people transcend the global discourse of HIV as an unquestioned death sentence (Toufexis, 1996). Based on ancient wisdom, recent evidence reveals the myth of an autonomous immune system: it shows how one's beliefs, feelings, attitudes and social surround are crucial in the course of disease and healing (Miller, 1997). When the ordinary does not pan out, we cannot negate that which is unique. The research presented may assist us to ferret out anomalies and concede that there is much to healing which our dominant paradigms disregard. Without ignoring the realities, I hope to show that a global health 'crisis' may have a silver lining contained within it (The Light Party, 1998; Saleeby, 1996).

This chapter will elicit how social work within a competence orientation, sits comfortably in the new conceptualisations of healing and disease. The literature herein is of a Western origin, yet in meeting a developmental criterion of appropriateness and without minimising cultural differences, the essential concept of 'connectedness' seems to parallel traditional African doctrines of holism (Sewpaul, 1995).

2.2 HIV AND AIDS IN A SOUTH AFRICAN AND GLOBAL CONTEXT: THE NEED FOR ALTERNATIVE RESPONSES

Defining AIDS is a controversial task. The HIV/AIDS hypothesis proposes that AIDS is not a single distinct disease, but a disorder characterised by severe suppression of the immune system, resulting in immunodeficiency. The HIV virus, argued to be the cause of AIDS, progressively infects the white blood cells of the immune system. The role of these CD4 cells and T-helper cells in clearing disease causing substances from the body, is hindered. The inability of the immune system to defend against pathogens renders the body susceptible to an array of normally manageable opportunistic infections. As a disease of time, HIV/AIDS is seen to progress on a continuum of stages from initial infection until death. Each stage is defined according to the degree of impairment of the immune system. Initially infection is 'asymptomatic' with no or few symptoms. Yet in a period of a few months to 10 years, CD4 and T-helper cells drop from a normal activity and range of 500 - 1500 in a millilitre of plasma, to below a count of 220 ml. AIDS, the name given to the fatal and final stage, is viewed as an inevitable consequence for the victim (Smith, 1999; Kestler, 1999).



This medical paradigm, underpinned by Newtonian dualistic and deterministic theory, attempts to isolate the infectious agent and develop a lethal drug. Challenging mainstream consensus, the multifactorial hypothesis proposes that there are multiple factors causing immunosuppression and all should be comprehensively addressed. It contends that the HIV virus mutates, rendering past immune responses ineffective. Medication may have toxic side effects and promote the emergence of drug-resistant strains. In adopting a holistic stance, this theory recognises the interdependence between the immune system and one's attitudes, emotions, thoughts and spiritual development. Hence, these factors become significant in the genesis of AIDS (Smith, 1999; Martin, 1997).

Within this dilemma lies the social construction of HIV and AIDS. As the dreaded disease is couched in a discourse of inevitability, the evolution of AIDS becomes the norm. Trapped helplessly, all succumb to a supposedly inescapable end. Almost as victims of a plague, those infected are a tainted community. The virus becomes the enemy, the disease an invasion against which the body cannot defend, and the epidemic becomes a war. These metaphoric trappings deform the experience of an illness and contribute to the prejudice and excommunicating of the ill. In a context where a social death precedes the physical, non-disclosure, fear, shame and guilt prevail (Sontag, 1990).

Sub Saharan Africa is the global epicentre of AIDS. Since the epidemic began, 34 million Africans have been infected and almost 12 million have died (UNAIDS, 1999). In South Africa (SA), AIDS has reached epidemic proportions infecting more than a thousand people a day. The disease is tearing apart families and communities, turning wives into widows and children into orphans. It is predicted that more than 2.5 million South African children will lose both parents to AIDS in the next ten years (Gore, cited in Treatment and Action Campaign, 1999). HIV's assault on young adults makes the disease both a social and economic disaster (Halweil and Brown, 1999).

The objective of development, within an international and national context, is to bring sustained improvement to the well-being of the individual, bestow benefits on all and reduce the vulnerability of individuals and communities to HIV/AIDS (United Nations, cited in Patel, 1992; UNAIDS, 1999). The South African welfare context, valuing an enabling environment, is rooted in distributive principles of inclusion, non-discrimination, equality and human rights (Gauteng Department for Welfare and Population Development, 1998). Yet the gulf between policy and practice is huge. The South African government is not supplying antiretroviral treatment. At a minimum of R770 per month, where more effective treatment sits at R4000 per month, medical treatment is unaffordable for most communities (Roberts, 1999). AIDS compounds the "vicious circle whereby socio-economic factors create vulnerability and HIV infection then creates new inequality" (Heywood, 1999: 5).

Already 70% of the beds in some South African hospitals are occupied by AIDS patients. South African health care systems are overwhelmed: clinics are short of drugs and staff lack adequate training (Halweil and Brown 1999). Yet in the developed world, AIDS is managed through science and access to treatment (Heywood, 1998). Sophisticated drug regimes such as triple therapy, provided by the public sector, need perfect compliance and are rarely possible in the developing world. The gulf

between rich and poor creates inequality of health resources within and between countries (Treatment and Action Campaign, 1999). "There is nothing in the whole AIDS mess that is not political" (Kramer, cited in Heywood 1998: 1).

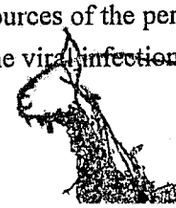
"We accept that a richer person can have a better car.. but there's something less acceptable about the rich being able to purchase more years of life" (Treatment and Action Campaign, 1999: 6). The question remains: what can be done about it? Should we wait for an affordable cure? Perhaps not. As a wake up call to the nation, we need to develop a critical culture in which we ask: 'is everyone infected with HIV doomed to progress to full blown AIDS?'; 'Why is it that people with HIV can and are preventing and reversing their symptoms?', 'Why is it that 8% to 10% of HIV seropositive people live productively as long term non-progessors with little or no damage to their immune system for at least a decade, some not developing AIDS in over 15 years' (Gorman, 1996). The focus on these stories, rarely shared in a context silenced by discrimination, alters the discourse of HIV and AIDS as a universal death sentence. Possibilities, hopes and the unknown remain tangible proof that the cause and outcome of the disease is not a given (The Light Party, 1998). The factors that account for this are unknown, but facts do not cease to be because they are ignored (Martin, 1997).

2.3 PAST AND PRESENT PERCEPTIONS OF HEALING AND DISEASE

For centuries, dualistic doctrines which regard the mind as a spiritual entity distinct from the physical body, have dominated Western thought. Medicare became the domain of physical causes, defects and rational cures. The role of thoughts, emotions and the environment in immunology was negated (Martin, 1997). Where disease was perceived as a viral invasion of the body, healing was founded on symptomatic relief, rendering the person powerless in helping themselves (Achterburg et al, 1994).

'Central state materialism' shifted this focus as it correlated internal mental states and overt behaviour. The mind became the brain, a *part* of the body governing behaviour and organs, and immune functioning was influenced by neurological and physiochemical processes. 'The double aspect theory' advanced this shift. Mental states were no longer viewed solely as accessible to scientific study. They were considered 'inner', accessible to introspection. Self consciousness, one's experiential reality, was recognised as an invisible factor related to bodily processes (Campbell, 1970). Transpersonal medicine then rejected that the mind was localised within the brain. Rather it was considered to be unbound by space and time. Connectedness among a cosmic community began to infiltrate the discourse of healing and disease. Alone, empirical knowledge became inadequate. That which could not be reasoned came to complement rational thought (Dossey, 1991; Achterberg et al, 1994).

Literature reveals how current perceptions of healing and disease reflect an integration of these paradigm shifts. Underpinned by the premise of mind, body and spiritual interconnectedness, deep healing moves beyond the eradication of symptoms, towards a process of learning and transforming root sources of disease. This involves a multiple identification of mental, emotional, social and spiritual sources of the person's life, coupled with the physiological factors of illness. A reductionistic focus on the viral infection is replaced with a holistic treatment of the *whole* person (Miller, 1997).



Where curing refers to restoring a person's pre-existing state of wellness, healing implies a return to wholeness in which all subsystems work harmoniously. It is a process that facilitates a movement towards a new state of being; it is a journey that occurs within. This unique journey comprises multiple factors: discovering internal behaviours that facilitate disease progression *and* pursuing harmony in relationships, intrapersonal transcendence, embracing fears, self expression, trusting life, living creatively and passionately, discovering inner resources, finding meaning, and feeling connected in conjunction with valuing the self. To travel this journey is to come into one's power, the highest level of health. These influential tools are in our direct control and render health, both individual and collective, our own responsibility (Miller, 1997; Collinge, 1996).

Within this healing discourse the concept of disease is transformed. No longer viewed as a linear process caused by the invasion of an external enemy, illness is an outcome produced by multiple interacting factors resulting in system imbalance. Disease becomes a physical message communicating an urgent need to re-evaluate one's life and alter the beliefs about one's self and one's relationship to one's world. Illness is not a permanent attribute, but an opportunity to engage consciously in a forward journey (Kaiser, 1993; Miller, 1997). It reminds us that "every obstacle *IS* an opportunity" and that it is each person's free will and unique power to evoke that transformation (Bittman, 1999: 2).

In moving from reductionism towards an integrative perspective of health and disease, we recognise healing as a three legged stool. One leg is for pharmaceuticals, another for surgery and the third comprises the natural pharmacology of attitudes, feelings and spirituality (Collinge, 1996). "Hope, faith.. and a strong will to live offer no promise of immortality, only.. the opportunity to experience full growth even under the grimmest circumstances" (Cousins, cited in Hafen et al, 1996: 460).

2.4 THE CONCEPT OF IMMUNOMODULATION

Only 50% of long term non-progressors have protective genetic markers, hence, it is likely that *other* factors play a role in blocking the progression of HIV (Buchbinder, cited in Jama 1999). As HIV directly attacks immune functioning, and AIDS refers to the presence of opportunistic infections under conditions of compromised immunity, the *power* of the immune system becomes crucial in maintaining the host's resistance to disease (Kaiser, 1993; Ader, 1991).

The immune system, composed of interdependent cells that defend the body against infections, utilises cell mediated immunity as its powerful component. This requires T-Helper cells (CD4) to co-ordinate the immune response, T cells and Natural Killer cells (NK) to target viral infection and Suppresser T cells to maintain a balanced immune response (Linnemeyer, 1999). Yet in HIV and AIDS, a progressive decline in the proliferation and activity of CD4 and NK cells results in immunosuppression (Barlow and Durand, 1995).

The activity of HIV depends on the conditions of the immune system's intracellular environment. If the environment is inhospitable and toxic, the virus mutates, rendering current immunity ineffective. To prevent viral replication and immune decline, stimuli received by the virus are altered. Such change

promotes viral dormancy in which the host T cell remains unaffected by the virus. Viral dormancy fosters an arrest or reversal of disease progression, as T cells stabilise or increase in number. If the CD4 cell count is low, other aspects of immunity may be strengthened (Kaiser, 1993). Hence, immunomodulation plays a crucial role in disease resistance. Rejecting the premise of an autonomous immune system, immunoregulatory diseases are considered multifactorial. This integrative framework promotes a search for potential avenues that access and enhance the immune system's intracellular environment (Ader, 1981; Ader, 1991).

2.5 MULTIPLE AVENUES OF IMMUNOMODULATION - A BIOPSYCHOSOCIAL PERSPECTIVE

"Wherever there is a heart and an intellect, the diseases of the physical frame are triggered with peculiarities of these" (Barlow and Durand, 1995). In speaking of the "bodymind", psychophysiological research has found complex pathways connecting the psyche, brain, endocrine and immune systems. The scientific discipline of Psychoneuroimmunology (PNI) explores the body as an integrated circuit and reviews how perception and emotions impact on one's physiology. Thus we discover how an interconnected informational network is implicated in disease expression (Miller, 1997; Hammerschlag, 1994).

Our state of consciousness influences how we perceive and respond to the world out there, past and present. Thoughts, beliefs, feelings and images held in our minds, produce a corresponding neurochemical environment in the cells of the brain. The brain, a biological system, communicates with the immune system through nerve connections and the language of peptides. These neurotransmitters, hormones and neuropeptides interact with the receptors of the immune system's cells. The immunocompetent cells then respond to these chemical messengers. Thus mental images, floating in a biological realm, create biochemical changes which influence susceptibility or resistance to disease (Miller, 1997; Ader, 1981; Ader, 1991; Hobson, 1994; Hafen et al, 1996).

If the brain influences immune responses, then the effect of psychosocial factors on immune functioning is implied. As patterns of electrical signals represent the external world inside the brain, our mental images interact with outside events. Thus, immune reactivity is influenced by external and internal factors. Hence, our life stories are told in chemical equations, as what we experience and how we feel changes the measures of immunologic strength (Hammerschlag, 1994; Miller, 1997; Ader, 1991; Hobson, 1994; Hafen et al, 1996).

2.5.1 The Interplay Between Social, Psychological and Spiritual Factors in Healing and Disease

"There is nothing either good nor bad, but thinking makes it so" (Shakespeare, cited in Martin, 1997: 117). Stress, a biological and biochemical process, begins with the perception of a physical, emotional or immune mediated threat. This perception spreads through the autonomic nervous system, causing the release of noradrenaline, adrenaline and the stress hormone, cortisol. In brief amounts these enhance immune function. When released persistently under chronic stress, this stress response results in immunosuppression (Hafen et al, 1996; Martin, 1997).

Couched in a systemic perspective, immune function is swayed by the interaction of internal perceptions and external realities. As thoughts and emotions trigger chemical neuropeptides, they link memory and conscious thought with inner physiology. Thus, psychosocial stressors pertaining to past, present or future events, may stimulate a stress response, adversely affecting immune function (Martin, 1996; Health Independent, 1999).

In a context where discourse has constructed HIV and AIDS as a death sentence, HIV positive people are vulnerable to chronic stress, anxiety, depression, social isolation, personal loss, hopelessness and helplessness. These feelings are reinforced by societal responses. Having a psychobiological impact on the individual, the stressors of the AIDS epidemic and individual responses to this, are cofactors in disease expression. Research findings support this interaction and show how these factors may be used in disease resistance (Ader, 1991; Martin, 1997).

Emotions, the mental markers of meaningful events, create memories that influence how we respond to our present situations. Overcoming difficult events in the past, creates positive memories and a sense of control. These feelings are crucial to immunity. World War II studies show that when people ate breakfast whilst reading the newspaper, ulcers developed. Negative emotions, converted into chemical changes, adversely affected health. When HIV positive people introduce positive emotions in place of fear and guilt, their T cell proliferation increases. Positive emotions and reference memories become significant in disease resistance (Kaiser, 1993; Miller, 1997).

Anxiety translates into a cognitive process of worry, which creates negative thoughts of *future* events. Kept in a state of semi-arousal, the body's adaptive response depresses immunity. When worry escalates, fear ensues. Fear results in negative expectations, triggering the stress response. This keeps the body in a chronic state of alertness, *directly* suppressing immunity (Hafen et al, 1996).

Defined as mental images based on *past experience*, fears determine our current coping responses. Fears deplete our energy, sense of choice, power and control, thereby indirectly affecting immunity. They distort reality, create passivity and paralyse hope. Yet, that which creates the self as a victim, may be the vehicle for transformation: A clarity occurs as one confronts the barrel of a loaded gun, denial fades and worrying becomes futile. One realises that one is living right now, that today is the tomorrow one hoped for yesterday, and that each day becomes one to *live fully*. Thus confronting fears is not diametrically opposed to being positive (Miller, 1997: 270; Hafen et al, 1996).

Fears develop as people perceive themselves to be alone. To lack a sense of belonging is defined as a human tragedy and the most generic form of stress. Those who maintain a sense of social cohesion sustain their health and recover from disease, more so than those who feel lonely. Loneliness results in an excessive secretion of cortisol and immunosuppression (Hafen et al, 1996; Stevens, 1994).

Linked to loneliness, the processes of loss and depression may accelerate disease expression. Loss often creates a state of intense depressed emotions. These result in a chronic release of cortisol,

directly depleting T and NK cell activity. Indirectly, loss influences coping behaviours of exercise, healthy eating and drug use, all of which impact on immunity (Hafen et al, 1996; Martin, 1997).

Despair results in a loss of perspective. People feel they have no choices, escape, or control over their life. Individuals, no longer steering the course of their destiny, are disempowered (Sahakian, 1997). This psychological entrapment leads to a sense of helplessness. Defined as the "given up complex", hopelessness enters the body. Unconsciously perceiving oneself as a victim, powerless in the face of towering events, the stress response is activated, reducing disease resistance (Hafen et al, 1996: 229).

In contrast, the *belief* that one can influence one's life, creates the perception of being in control. This thought buffers the stress response and influences behaviour. As people develop the "fighting spirit", they assume responsibility, take *action* against disease progression, develop a desire to survive, a sense of purpose and attitudes of faith and hope. Perceptions and action marry in mobilising a failing immune system (Hafen et al, 1996: 526).

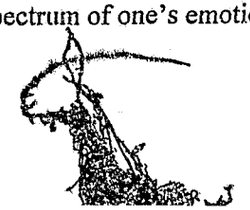
Hope, a positive expectation and m dical instrument protecting against disease, promotes future oriented attitudes of possibility and optimistic outlooks. This internal attitude has direct and indirect influences on immunity: Hope causes electrochemical changes in the human body, which influence the strength of immunity and it propels health supporting behaviours (Hafen et al, 1996).

Laughter, a psychophysiological reflex, promotes a short release of adrenaline and pain-relieving hormones, and suppresses the production of stress hormones. Psychologically, humour enhances one's self esteem, decision making skills, coping capacities, sense of balance and power. Hence, laughter is pertinent in preventative and healing processes (Berk, 1989; Hafen et al, 1996).

The link between loneliness, depression and hopelessness, brings forward the notion of connectedness. "All diseases are social.. a breakdown in social support.. precipitates a breakdown of.. immune functioning". Feeling valued, connected and having informational and material support, provides tangible and intangible resources. These enhance positive emotions, self esteem and a sense of control which interrupt an immunosuppressive stress response (Hafen et al, 1996: 262).

Connectedness involves the process of helping others. This releases natural endorphins, producing positive emotional states. Altruistic beh viour, defined as a miracle drug, has beneficial effects for the helper and the helped. Similarly, it stimulates a healing response in those who observe it at a distance. This may be couched in terms of chemi dorphins or perhaps in the process of returning to our larger, undivided self (McClelland, cited in Dossey, 1991).

Social support lends itself to emotional expression. The suppression of emotions blunts awareness, which isolates us from past experiences and information for making choices. Yet, by regaining access to a full spectrum of one's emotions and releasing these emotions when their time has passed, isolation



is reduced and the exploration of feelings and beliefs is promoted. These factors correlate with an increase in CD4 and T cell activity (Kaiser, 1993; Collinge, 1996; Miller, 1997).

Beliefs, which underpin our perceptions about the world, impact on our physiological response more so than the world itself (Miller, 1997). The meanings one *chooses* to give to support, disease and loss, are bound in *culture and past events.* These meanings produce mental images that generate changes in the body, modulating internal and external factors at a cellular level (Locke, 1997). The notion that "belief becomes biology", is evident in the "placebo response". Pain relief occurs when a pill with no biological effect is consumed by one who believes in its effect (Cousins, cited in Dossey, 1991: 57).

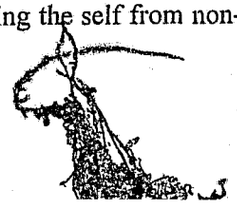
Meanings applied to situations affect human resilience and initiative. What determines the crisis of AIDS is not the illness, but one's coping style. Those who remain angry disconnect from the world. With a resentful attitude of 'nobody cares', people cut off from life sustaining processes of give and take, prompting a chronic stress response. Those who imagine possibility, perceive change as a challenge, commit to engaging with the self and others, refuse to feel powerless and develop proactive strategies to cope. These factors interrupt the stress response, increasing resistance to disease (Hafen et al, 1996; Locke and Colligan, 1997).

Optimists reinterpret negative perceptions of an event. As the focus shifts towards the potential for *learning and change,* a crisis is reframed as an opportunity. Positively framed perceptions affect one's sense of hope, control, ability to engage with others and channel positive thoughts through the system. Pessimism, which throws the body into a stress response, fosters feelings of powerlessness and passivity. In changing negative attitudes, people alter their disease environment (Hafen et al, 1996).

Social constructions of HIV and AIDS shape one's feelings of guilt and shame. This internal stress, linked to depression, isolation and apathy, is advanced through one's negative self talk which activates the stress response. In recreating an inner reality, people choose their internal messages, separate the 'me' from the 'you', rewrite their past and present stories and establish a script for the future. These actions of choice and change foster success and healing (Miller, 1997).

To heal is to make whole, to integrate and attune all levels of the system. The focus has shone on the interaction of mental and physical health, yet to explore holistic healing within its dynamic balance, spirituality, the healing journey within, is essential. This journey uncovers a paradox. It provides for the discovery of self *and* reveals a healing bond among all people, [illegible] the universe. This emotional and spiritual path directly affects T cell proliferation (Dreher, 1995; [illegible]tmar[illegible], 1999).

Self discovery lies at the root of healing. As HIV enters the T cells, the im[illegible]e system is clouded in distinguishing the self from non-self. As HIV is socially constructed, on[illegible] own beliefs are lost in the



judgements of others. Developing an authentic self cleanses this confusion: One's thoughts become distinct from others, and the virus is perceived as separate from the self (Miller, 1997; Stevens, 1994).

The journey of discovering one's value and worth is a paradoxical process. It is a path in which one learns who one is, accepts and expresses this truth, yet urges oneself to change. Mental images of this self create a preferred neurochemical pathway. Similarly, the process of honouring the self creates an inner peace, by which one challenges the expectations of others. Self esteem and efficacy are the keys to personal competency. They unlock inner resources of resilience, internal control and a capacity to cope with challenges. Thus physical health becomes an expression of the self (Miller, 1997).

To discover the self, people revise their assumptions about their identity and the world. In consciously selecting beliefs which influence perceptions and behaviour, people create their own experience of reality and unleash the process of self responsibility. The ability to respond to life events, evolves as people view themselves as distinct from their minds, emotions and bodies. By guiding their thoughts, feelings and behaviour intentionally, people assume responsibility for their well being (Miller, 1997).

To fully comprehend 'responsibility', the traditional African paradox of "freedom in dependence" elicits how autonomy of the human being is attained through interaction. As all systems blend together in a single song, self realisation requires an influence from other persons (Schutte cited in Sacco, 1996: 37). As one learns to love the self, one recognises that it is not only in receiving, but in teaching rather than being taught (Miller, 1997).

Within spiritual health, personal and social responsibility become interdependent. One attains a sense of peace in relation to the self and the environment, a feeling of being in control of one's responses to the environment and a sense of relatedness within the self and with others (Hafen et al, 1996). This brings meaning to one's life, motivating the will to live. In transcending individuality, the self is seen as part of humanity. This restores the bond between the human being and the cosmos (Dossey, 1991).

Spirituality rooted in action, not just belief, interrupts the production of immunosuppressive chemicals. Prayer, a psychological activity in connectedness, induces a state of relaxation, gratitude, hope and emotional release. It assists one in restoring perspective, nurturing the self, others and developing a sense of trust. Consciousness as a non-local field, highlights how in 'distant healing', the effects of prayer are independent of the awareness of the individual. Similarly, the act of forgiveness releases past hurts, guilt and loss from the mind. In freeing one from chronic fear and hostility, a pathway towards the acceptance of self and others is created. As conflict between the self and other is replaced with a co-existence, energy shifts from battling the other towards productive living. Wholeness, balance and transformation is fostered (Dossey, 1991; Hafen et al, 1996; Sahakian, 1997).

2.6 HOLISTIC HEALING IN THE CONTEXT OF SOUTH AFRICAN SOCIAL WORK

It seems as if there are parallels between holistic healing and the prevailing approaches to social work. The current South African social welfare system is couched in principles of empowerment, aiming to release people's creative energies and facilitate self determination. Individuals are "afforded the opportunity to play an active role in promoting their own well being". Thus, the paradox of self reliance *and* participation is encouraged in this realm. Similarly, the principle of Ubuntu, which explores how the self develops in community, elicits that individuals have a responsibility to promote individual and societal well being (White Paper for Social Welfare, 1997: 7).

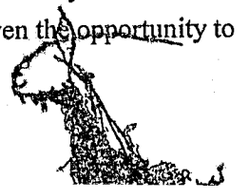
Within this macro context, the purpose of social work is embedded in developmental paradigms and systemic thought. Ecological competence emphasises the interplay between the person's internal capacities, cognition and motivation *and* the qualities of his or her environment. Social work shifts from paradigms that regard the client as inevitably incapacitated, towards those that locate strengths and resources on an intrapersonal, interpersonal and macro-level (Germain 1984; Whittaker and Tracy, 1987). In a context of holistic health, all these levels interact to facilitate the process of healing.

Enveloped in this competency orientation, social work's purpose reflects beliefs in the client's capacity to change, grow and exercise choice. It emphasises processes of coping and adaptation, and highlights that every human being, propelled by thoughts of future possibilities, moves towards their potential (Mallucio, 1981).

Yet, as I read the section on HIV and AIDS in the White Paper for Social Welfare (1997), the content seemed to focus on other people's attitudes, social support and AIDS care. I recognised a gap in the exploration of self reliance. No reference is made to the notion of disease resistance and educating societies on their potential to heal. The focus is outwards, as opposed to a holistic perspective of inward development *in conjunction* with external factors. The White Paper for Social Welfare (1997) classifies those with HIV and AIDS as a 'vulnerable group'. Such discourse may have serious implications for people's perceptions, thoughts, sense of self and coping behaviours. Social construction in this realm may influence disease progression.

2.7 CONCLUSION

In discovering the miraculous web of life that joins us together as a larger whole, we take cognisance of the human mind and its ability to experience the weaving together of thoughts, feelings and images. Through this we master the art of creating meaning and healing (Miller, 1997). From an eco-systemic framework, social workers are searching for alternative approaches to helping, disengaging from dominant Western dualism (Sacco, 1996). Perhaps the profession may adopt a broader perspective of healing, one that goes not only to the depths of the individual, but beyond, to our families, communities and ultimately the planet as a whole (Miller, 1997). Hence, qualitative methodology, that prizes subjectivity as the real source of knowledge, awakens us to the mysteries of life. As such, social work is given the opportunity to grow through multiple perspectives (Sacco, 1996; Fook 1996).



CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

3.1 RESEARCH APPROACH AND ITS UNDERLYING ASSUMPTIONS

"Partners in discovery" is the title used by Goldstein (1991) in exploring the realm of qualitative research, where 'partners' indicates that the process of scientific enquiry is a collaborative venture between the researcher and respondent. Unable to detach from the social world studied, the researcher is actively immersed in the process of investigation, eliciting participants' accounts of meaning, experience and perception. Resisting positivistic notions of dualism and value freedom, such research contributes to an enriched understanding of the human experience (Elliot, cited in Lincoln, 1995; De Vos, 1998).

The presumption that knowledge is gained directly via a process of participation, merges with the relativist ontology that all social realities are mentally constructed and can only be reflected by those personally experiencing them. These constructions are realised in the sharing process of narrative and discourse. Realities are thus multiperspectual and democratically arrived at (Eisner and Peshkin, 1990; De Vos, 1998). The epistemological assumption of subjectivity and interaction, reaffirms the ontological importance of experiential and interconnected ways of knowing (Fook, 1996). This phenomenological alternative, which views behaviour as determined by an internal reality, complements positivist orthodoxy, similarly to the way in which the eco-systemic approach seeks a holistic explanation of social challenges (De Vos, 1998).

In perceiving that consciousness is active in meaning making, it is assumed that nothing can be known with certainty. Truth becomes based on our own reactions to an event and objectivity evolves purely as a process of inquiry. The reciprocal influence of the narrative, analysis and context brings doubt to the correspondence theory of truth, as all forms of representation become partial and understanding is based on the interpretation of reality versus reality itself (Eishner and Peshkin, 1990; Fook, 1996).

To this end, research findings aim to describe, make sense of and reconstruct social interactions in terms of subjective meanings (De Vos, 1998). A-priori assumptions are reserved, giving primacy to the emic perspective, in which "natural attitudes" are individually held and intersubjectively shared (Goldstein, 1991: 105). The theory that *follows* research is glossed with meanings, recognisable by those to whom it applies (De Vos, 1998; Cohen and Manion, 1994). Such methodology helps change power relations and preserves social work values of individuality and self determination (Saari, 1991).

Given these qualitative assumptions and having recognised mainstream sentiment that equates HIV and death, coupled with the marginalisation of HIV positive people, I chose to use a narrative design. Narrative became an efficient strategy to yield the complexities of the knowledge sought (De Vos, 1998). It allowed me to investigate the stories of the HIV positive respondents and ascertain how disease resistance and healing is experienced subjectively, as their stories are constructed within as opposed to "out there" (Saari, 1991: 5). Although the definition of narrative is controversial, I prized Riessman's (1993) conceptualisation which defines the story as an essential meaning-making structure

and which recognises how individual agency determines what is included and excluded. This permits the reconstruction of a coherent self in a time of illness when the self is supposedly disembodied.

The narrative approach promotes relational research, valuing the connectedness between the researcher, respondent, community and society (Lincoln, 1995). As the respondent translates his personal knowing into telling, the listener is transferred through conversational discourse into his past world. As such, stories sanction access to personal meanings and reveal cultural influences (Riessman, 1993). A non-essentialist understanding of HIV and disease resistance develops as the emic perspective promotes theory built on real lived experience (Brunner, cited in Goldstein, 1991).

Saari (1991) recognises the reflexivity of the research process: human beings create themselves through the narration of their lives and in turn facilitate the development of others who interact in the storytelling. As such, in the joint construction of meaning, narratives become the instrument of empowerment, both on an individual and collective level (Eisner and Peshkin, 1990; Saleeby, 1994).

3.2 DESCRIPTION OF METHODOLOGY

3.2.1 The Research Process

This summary outlines my methodological processes, which are detailed in the sections that follow.

- A literature search ignited the process of data collection. This clarified preconceptions of HIV and AIDS, mind-body healing and the international and national supportive healing environments. Such clarification assisted me in developing a sensitivity to the respondents' frame of reference.
- Prior to individual in-depth interviews, four potential respondents were individually contacted by telephone and two followed with face to face meetings. Briefly, each respondent shared his views on HIV and healing, generating beginning concepts as a base for the interview guide. To gain informed consent and highlight issues of confidentiality, each respondent received a letter outlining the purpose and nature of the study (See appendix A).
- Using the dialectic between emic and etic perspectives, an in-depth interview guide was developed to facilitate a process of narrative telling (See appendix B). Two face to face interviews were conducted with each respondent, each interview lasting approximately 75 minutes.
- The discourse gleaned was tape-recorded and methodically managed. Using a mix of Siverman's (1993, cited in Poland, 1995), and Poland's (1995) transcription symbols I attempted to systematically transcribe the narratives that unfolded within the interaction (See appendix E).
- The cycle of data analysis unfolded as a succession of spirals, each at a higher level. A manual content analysis, in which I suspended preconceptions, allowed me to immerse myself within the respondents' descriptive accounts. Through open and axial coding, concepts became clearly distinct and synthesised, developing new constructs within the conceptual framework.
- Engaged in the interpretative act of writing up the findings, I attempted to capture the essence of disease resistance as experienced individually and collectively by the participants. Through recontextualisation, the results of the research are discussed in the light of relevant literature, identifying both common and unique contributions. My initial assumptions are revised and

recommendations related to the overarching purpose of social work are based on this revision, leaving open the realm of further analysis and description.

3.2.2 Sampling Procedures

The sample group of three asymptomatic HIV positive men emerged through the research process. As I gained a holistic understanding of the research topic, parameters for the constitution of the sample were identified. Access to the HIV and holistic healing subculture began a snowballing process of referral. This non-probability sample was selected purposefully according to criteria of accessibility, duration of an asymptomatic HIV status, belief in the power of self-healing and information richness. Maximum variation sampling resulted in a heterogeneous sample of one black and two white males, differing in ages and duration of HIV status. Diversity fostered a search for unique and common experiences allowing for both constructivism and critical constructivism. This small sample, rich in quality, cannot make claims on generalisability or representativeness, yet promotes idiographic insights into the elusive human experience and provides a new brand of fertile knowledge (Goldstein, 1991; De Vos, 1998).

3.2.3 Data Gathering Methods: Individual Narrative Interviews

The unstructured interview, described as a two person conversation between equals, in which meaning is made of the respondent's subjective world, became the means of gathering relevant research data (De Vos, 1998; Cohen and Manion, 1994). The research tool I constructed is discussed in 3.2.4. Each of the three respondents agreed to be interviewed individually for approximately one hour, on two separate occasions. Two of the respondents and I engaged in separate brief discussions prior to the entire research process.

As I immersed myself in the available literature and participated in psychoneuroimmunology courses, so I identified the boundaries of data to be collected. Individually, the respondents were briefed regarding the nature and purpose of the interview. Their informed consent to record the interaction on audio tape was granted. It seemed as if the mutual respect and rapport that this generated, outlined by Lincoln (1995) as core criteria of the qualitative approach, facilitated the process of interaction and narration.

Each individual interview seemed to promote subjectivity as I became intimately involved within the interaction, not minimising reactivity or reciprocity. The interview provided a medium of active engagement, as I listened and responded to each participant's account of his experience. Through the interactive process of talking and listening we produced a narrative together, experiencing the research criterion of reciprocity (Riessman, 1993; Lincoln, 1995). Thus, the respondent and I journeyed as a learning community, open to being informed and transformed as a result of the inquiry. Hence data gathering was not restricted to understanding the content of inquiry, but the process itself (Eisner and Peshkin, 1990).

The 'voice' of each respondent became his tool to express meaning and experience. This was immediately recorded (Riessman, 1993). In preserving the sound of language, the transcription process

in which I attempted to represent the narrative in the form of text, was facilitated. Each transcript in itself became an object of research (Poland, 1995). Nonetheless, I share Nietzche's concern that a gap exists between actual experience and the community of experience (Nietzche, cited in Riessman, 1993). The gap is widened as the verbal recordings did not capture the deeper emotional and non-verbal dimensions of the interaction. Furthering this breach, the verbatim transcriptions fail to capture the rhythm of what was said. Thus data gathering becomes an interpretative process, resulting in a world of knowledge one step removed from the original voice (Riessman, 1993).

I found that in transcribing the narrative immediately after the initial interview, I was able to shift further into the respondent's closed world. This facilitated the data collection process as I deepened my insight and scope of inquiry, by adding probes to the interview guide in preparation for the second interview. This enhanced a mutual production of knowledge and fostered a heightened understanding of the respondent's unique experience.

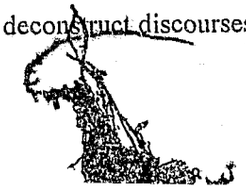
3.2.4 Research tool

The narrative interviews, as a mode of systematic inquiry, elicited an 'insider view' of disease resistance and management. In facilitating an in-depth learning of these closed worlds, the interview guide was utilised as the medium of research. This research tool, containing questions and themes significant to the research objectives, fostered loosely structured individual views and propelled an interactive process of conversational discourse, in which the respondent and I became constructors and not conveyers or receivers of knowledge (De Vos, 1998; Goldstein, 1991). Thus the interview guide fostered a shift from linear, analytic thinking towards constructivist thought, as data elicited was shaped in human meanings, not statistical variables of cause and effect (Lincoln, 1995).

As qualitative research does not occur in a theoretical vacuum, available knowledge and research was used as an informative map of the terrain to be explored (Goldstein, 1991). The research schedule was underpinned by knowledge gleaned from theoretical literature covering specific aspects of inquiry, my personal connections to those suffering the effects of chronic illness and the beginning concepts of the respondents captured in telephone conversations and initial meetings (Woods, 1995). As such, the research guide lies in reciprocal relationship to data gathering and analysis, in which a dialectic between grounded theory and deduction emerges.

3.3 METHOD OF DATA ANALYSIS

In claiming that "there are no external, absolutely conclusive standards with which to judge the social phenomenon under scrutiny", the reflective mind of the researcher is regarded as the principle medium of analysis (Hammersley, cited in Goldstein, 1991: 104). As we shape the data obtained using interpretation and creativity, analysis becomes an interactive approach, clarifying the dialectic between induction and deduction. In this journey, analysis is a product embedded in an iterative process in which we deconstruct discourses and uncover multiple meanings (Dey, 1993; Fook, 1996).



The vigorous transcription process assisted me in familiarising myself with the data. Then, through open coding, I began a process of data reduction, abstracting from the complexity of the data those features I found most salient. I explored the data sequentially, coding according to a line by line, phrase by phrase and even a single word approach, considering each bit in detail. I identified recurring themes, language and patterns of belief within each colour coded transcription. I removed bits of data out of context and grouped seemingly similar observations into categories of meaning, each symbolising a similar class of events (Dey, 1993; De Vos, 1998).

The transfer of data from its original context to assigned categories allowed me to draw boundaries between different concepts, searching for internally consistent and distinct meanings. Categories were meaningful both internally to the data and externally to other categories. As I interacted with the mass of data, so the criteria for inclusion and exclusion into each category changed and through splitting, I created sub-categories that promoted a refined analysis (Dey, 1993).

Axial coding, a process of splicing categories, allowed me to make connections within and between categories, weaving the information into a connected whole. Thus, the process of differentiation was balanced with a process of integration. I explored regularities within and across transcriptions and counted how many times observations were repeated. Counting concepts determined meanings of what was similar. In part, synthesis was informed by numbers, creating a dynamic balance of quantitative and qualitative forces. We do not only want a number of scattered trees, but a wood (Dey, 1993).

The categories created provided a conceptual framework to understand disease resistance and management. Writing an account of my findings became an integral part of the analysis process. I finally discovered a metastory, interpreting, editing and reshaping original narratives and categories. In creating this hybrid story, underpinned by both first and second order constructs, narratives were reborn in an "alien tongue" (Riessman, 1993: 13).

As I suspended prior knowledge, categories of meaning emerged from first order constructs within the data itself (Dey, 1993; De Vos, 1998). Yet, these categories did not merely reproduce the data. They created new views related to the research purpose and my own reflection. Within the criteria of credibility and neutrality, I attempted to slice my assumptions and rigorously create an accurate representation of the human experience. However, I simultaneously valued relational research. Thus, the process of analysis was an interplay between contradictory terms of induction and deduction, respondent and researcher, data and categories, rigour and creativity.

3.4 LIMITATIONS OF RESEARCH DESIGN AND METHODOLOGY

3.4.1 *Whose* reality is elicited in the process of constructing meaning? I concur with Riessman's (1993: 15) debate that narratives and texts represent reality partially and selectively, and ambiguous meanings are shaped by the research relationship: My research findings have arisen out of a process of

interaction between the teller, recorder and myself as listener and analyst. Although I attempt to present neutral data, I view myself and the context as integral to the research process. My analysis is therefore contextual and a product of the subjective mind (Riesmann, 1993: 15).

3.4.2 I chose to acquaint myself with existing literature prior to the narrative interviews. As such, I may have unconsciously agreed with responses that conformed to my values and expectations and been less sensitive to negative instances (Cohen and Manion, 1994). To avoid inhibiting the inductive process I attempted to carry out the inquiry with a heightened awareness and an openness to criticism, defined by Popper (cited in Eisner and Peshkin, 1990: 34) as the 'critical spirit' and Lincoln (1995) as critical subjectivity.

3.4.3 Having no women within the sample may be viewed as restrictive, limiting generalisability and representativeness. Yet in a realm where subjectivity is prized and multiple realities acknowledged, the issue of generalisability is overshadowed by the enrichment of understanding. The difficulty in attaining women to fit the research criteria seems to reflect power relations in broader society. This lack of 'voice' "echoes the cry for passionate participation" and reinforces the notion that qualitative research is first a "community project" (Lincoln, 1995: 282).

3.4.4 The transcription process revealed inherent differences between the spoken tongue and the written word. Transcription as an interpretative process is a limited account of a much richer interactive encounter. This reflects the notion that as a researcher I do not have direct access to another's experience and I am limited in transmitting its full flavour (Riessman, 1993; Poland, 1995).

3.4.5 The process of analysis involved the fracturing of texts as I edited snippets of the narratives out of context. Mischler (cited in Riessman, 1993) critiques this as a suppression of narrative. With this I concur, yet recognise this dilemma in the context of qualitative research, wherein "uncontaminated truth, cannot be established" (De Vos, 1998: 246).

3.4.6 As 'snowballing' may generate a sample of people who are similar, the sample group may reflect a bias (De Vos, 1998). This lies in opposition to a positivist notion of random sampling, yet the reciprocal influences between the respondents, became crucial to reflecting healing as a systemic issue.

3.5 CONCLUSION

As the narratives were rooted in subjectivity, in time and place, so a qualitative approach prompted an enriched understanding of the human experience and the process of healing. These stories, socially constructed, are now revealed and open to reinterpretation (Riessman, 1993; Poland, 1995).

CHAPTER 4

PRESENTATION OF FINDINGS

"There is no view from nowhere, no way to see the world as it really is, separate from ourselves and language" (Ford, cited in Riessman, 1994: XIV).

4.1 INTRODUCTION

In the metastory that follows, I attempt to lend shape to the respondents' journey with HIV. My passion for this topic prompted an experience in which I found parts of myself transformed. Thus, in striving towards the essence of their experience, these findings may bear the mark of my reality. As I moved reflectively between the literature, my views and the respondents' narratives, my interpretations may elicit a combination of induction and deduction. To maintain the integrity of these stories, the findings are explored using interpretative categories and the participants' spoken words (Woods, 1998)

4.2 DESCRIPTION OF RESEARCH PARTICIPANTS

	DAVID	PAUL	LUCKY
Age:	38	51	30
Family of origin:	Birth mother Afrikaans, Birth father unknown. Sister: Adoptive parents.	Parents divorced, father drinking problem.	Close nit, biological mother and stepfather.
Current views of family:	Male lover and female best friend.	Extended: all people in Paul's sphere of life.	Lucky's mother and his two children.
Children	None.	Two adopted boys.	A boy and a girl.
Language:	English.	English.	Zulu.
Culture:	Non-specific.	English.	Zulu.
Current relationships	Male lover.	Male lover of 14 years.	Mother of his children.
Current health status	HIV+ asymptomatic. Had symptoms in past.	HIV+ asymptomatic.	HIV+ asymptomatic.
Medication	None at present. Briefly used in past.	Never used.	Never used.
Duration of HIV status	16 years.	14 years.	7 years.
T cell count	Maintaining at +/- 1000.	Maintaining at +/- 300.	Maintaining at +/-700.
Viral load	Almost undetectable.	unknown.	unknown.
Current occupation	Empowerment training around HIV and AIDS.	Headmaster for eleven years at current school.	Newspaper columnist. Topic: HIV and AIDS.

Table 1: Description of Research Participants

4. 3 CATEGORY CONSTRUCTION: MAKING SENSE OF THE DATA

4.3.1 Self Perception

David (D), Paul (P) and Lucky (L) recognised themselves as worthy individuals, with qualities of assertion and leadership: *"I think what I want..I don't nee-ee-d you to give me value..I value myself" (D:1).* As themes of resilience emerged, not one respondent regarded himself as powerless: *"I'M NOT A VICTIM" (D:1); "I'm..against whining and winging..I am..a doing person" (P:1); "I am a wee-ee-d..I'm one of those turds you can't flush" (D:1).* Commonalities in their ability to teach and support others emerged: *"I have a strong influence over people" (L:2); "I love to offer support" (D:1).* In describing 'others' as *"over logical,.. compartmentalised in life" (P:2),* P portrayed himself as enjoying the messiness of living. All respondents described their 'self' in relation to others: *"my be-e-e, is I love you..my love of humanity" (D:1).* Contrary to

self descriptions couched in death, respondents created a perception of well being: *"I'm healthy look at me" (P:1); "Who I am :- not infected with anything..it's infected with terminal life" (D:1).* Where L related his 'self' to an economic realm: *"I'm..as poor as a church mouse" (L:1)*, P refused to link his identity to negative concerns: *"It's not in my nature to accept negative things" (P:1).* Although D made reference to having a positive outlook: *"If I was to get a lemon I make lemonade" (D:1),* he was the only one not to describe himself as a positive person *"I'm not positive"; "I'm realistic" (D:1).* All respondents defined the 'self' as courageously facing reality: *"I'm not one that runs away from fear" (D:1); "I'm honest" (L:2).* D, L and P reported to be: *"hugely impatient" (D:1)* and *"humble" (P:2),* which relate to the following theme.

4.3.2 Sense of Purpose: Will to Live

Respondents utilised a discourse symbolic of forward movement and future possibilities. This overshadowed perceptions of victimhood and depression, denoting inactivity: *"I was clear that I was here for a reason"; "creating a compelling future" (D:1).* Linked to this is the purpose of self development: *"if I was to..sin..it's not to be-e, who g-d intended me to be" (D:1).* Their humble quality seemed to create room for future growth: *"the more you know the less you know.." (P:2); "I am just on the..first rung of..a very exciting ladder (P:2).* P and L valued the present and future: *"I look..forward to life"; "to continue" (L:1,2); "on a daily basis new discoveries" (P:1).* P and D's impatience seemed to fuel a sense of future: *"I've got too many things to do still" (D:1); "I have to live to a hundred and fifty to do what I have to do" (P:1).* This sense of purpose relates to the coping mechanisms of hope, active planning, learning and the capacity to let go, where one is no longer stuck in the past: *"release and move forward" (P:1).*

4.3.3 Fear, Despair and Anger

In relation to their initial HIV diagnosis, D and L made reference to a sense of fear and despair: *"a frightening period"; "tears streaming down my face"; "talk about the dark night of the soul" (D:1).* Coupled with this despair, D seemed to maintain an element of hope: *"my entire world fell apart.. travelling..the world trying to find the elusive cure" (D:1).* L seemed to slip into inactivity and escapism: *"I spent most of my time sleeping"; "whether to rob fidelity guards..so they can shoot you..just so you don't die of AIDS" (L:1).* D and P expressed initial anger: *"initial discovery extreme anger"* (P:1). Where D and P did not refer to current despair, L recognised the context of social despair: *"we are still struggling about issues relating to..disclosure, the stigma" (L:2).* This theme of despair is related to social discrimination and victimhood.

4.3.4 Discrimination and Victimhood

All three respondents explored the reality of stigmatisation and its' impact on isolation: *"I experienced the prejudice"; "people would..avoid us"; "the nasty phone calls the bomb threats" (D:1).* L identified how such fear maintains secrecy, hindering the coping mechanism of disclosure: *"people are scared to come out" (L:2).* P reinforced how the beliefs of others have a direct impact on one's sense of helplessness: *"immediately people perceive you have this..then you have negatives coming at you"; "Oh poor Paul, SHAME"; "sometimes you fall into that trap.. why me" (P:1).* Likewise D expressed how at one point he lay stuck, unaware of his choices and capacity to effect change: *"I was in effect of my circumstances"; "I was abandoned.. I was caught up in that for a long time"(D:1).* All three respondents rejected victimhood and dependency as negative forms of connectedness, inequality and negation of 'self': *"I never foster dependency..or me giving me all of their power" (D:1).* L extended this to the current social context which

fosters disempowerment: *"they're doing things for the people"; "there's no active participation of PWA's" (L:2).* Powerlessness seemed related to how one defined the 'self' in relation to others: *"my inability to differentiate me-e from you..it's..you under me and, there's this..power struggle, the..victim..triangle" (D:1).* D critiqued the literature that proposes health benefits of social support and indicated how it may reinforce victim consciousness: *"they were sup[illegible]t groups that I call bitching sessions..all people did was.. fucking whine" (D:1).* In discussing a friend who died, P explored how feeling the victim fosters disease progression: *"he believed there was nothing he could do, (mimicking voice) "I've got it.. I'm going" (P:1).*

4.3.5 Making Sense of Death and Dying

All respondents seemed to have faced the reality of death. For D, this was initially prompted by others' perceptions of HIV: *"you're gonna die-ie"; "you've got about six months..left t-to live" (D:1).* For D, P and L, dying, accepted as a natural part of living, was not associated with finality, but a humbling experience allowing for a continued process of growth: *"death is natural" (L:2); "I'm not dead.. just moved onto a different level" (P:1).* Although P explored death in a positive light, a contradiction seemed to arise: *"it's not going to be a miserable funeral"; "I..had another near death experience..a very..bad experience" (P:1).* This interplay between positive and negative perceptions follows in the next theme.

4.3.6 Creating Meaning from Disease

The meanings respondents have given to HIV have evolved over time. As their past perceptions were influenced by societal discourse, HIV was associated with death: *"because of all the crap that was flying around..it meant a death sentence" (P:1); "the end of the road" (L:1).* The present discourse used by respondents frames HIV in a spiritual context of growth and opportunity: *"AIDS has been the biggest lesson for me"; "given me a clearer understanding of g-d" (D:1); "it's not about death..it's a life sentence" (P:1); "it was a blessing" (L:1).* HIV seemed to communicate a need to awaken: *"this is your wake up call" (P:1); "g-d's trying to give you a..message here" (D:1).* Yet respondents explored how positive perceptions of HIV were not a given, but a matter of choice, separating one's own beliefs from others: *"it's not the big boogy, that everyone makes it out to be..it's what you make it out to be" (P:2); "I don't believe AIDS is a gift ..it's what I've extracted from it" (D:2).* In developing a balanced perspective, respondents seemed to feel connected to and separate from the virus: *"it's a five percent portion of your existence it's not the portion" (P:1); "I am me.. it's only a small part of me" (L:1).* D's physiological understanding of HIV, reintroduced this theme of separating 'self' from 'other': *"HIV at an immunological level..is an identity crisis..it's inability to differentiate self from non-self".* Although L regarded HIV as part of the 'self', a power dilemma emerged as he defined HIV as: *"a formidable opponent"* and: *"a parasite" (L:2).* Similarly L showed conflicting meanings of HIV as a blessing and a fear: *"HIV has opened up opportunities"* and *"has..the potential to destroy one's life" (L:1).* For D and P *"HIV is..boundaryless"; "we co-exist" (D:2).* This elicits greater integration, as metaphors of battle are replaced with a: *"whole empowerment process" (P:1).*

4.3.7 Perceptions of Healing

Respondents' perceptions of what it means to heal has shifted over time. Past perceptions were embedded in a sense of hopelessness, lack of choice and dichotomous medical thinking: *"initially I..did not think about healing...it was not..a consideration" (L:1); "cause effect type reaction..have a headache take an aspirin" (P:1).* Current perceptions seem to elicit holistic themes: *"holistic attitude to healing..it does*

involve the mind..the spirit..the body..back to the balance of the triangle" (P:1). Healing seemed to relate to a sense of power, trusting the self and developing the self as an expert in the healing process: *"the more information I get..the more..confident I became..the process of healing started then" (L:2). "Listen to your body..you fill what's empty..empty what's full and..scratch where it itches" (D:1).*

4.3.8 Life History: The Process of Learning and Empowerment

Past experiences of the respondents seemed crucial to the development of powerful belief systems and current coping styles. D explored how his past, filled with rejection, assisted him in developing self acceptance and a sense of worth: *"exploring my sexuality..with other boys..the standard line in my house was (mimicking voice) "I was a disgusting little boy..a poofy child"; "I knew I wasn't..I knew I was a good person" (D:1); "They had something about.. (mimicking voice) "a fucking cock sucking queer".. something inside me said (mimicking voice) "that's not who you are, that is such a small - part of who I am..I'm multifaceted I can't be this disgusting..human being" (D:1).* P's life history seemed to teach him to externalise and adopt a problem solving, action and future orientation :*"I learnt through my hospice training..when you are working with people who are terminal let them blow"; "part of my growth into letting go"; "I come from that philosophy..look at the situation, assess it and do something about it..don't whine..make a decision.."; "my philosophical background..reincarnationist theory" (P:1).* L traced his current self assertion and problem solving capacity back to his childhood:*"I grew up with my stepfather"; "he instilled this sense of..if you don't want to do something say so"; "He said.. (mimicking voice) "..the time.. you've wasted crying..you could have been thinking about a solution to your problem" (L:1).* P and L engaged in what literature depicts as the survivor mentality (Miller, 1997): *"somehow y'know..you..survived whatever predicament you were facing" (L:1).*

4.3.9 How Past Difficulties are Processed as Opportunities for Growth

Commonalities in the respondents' gratitude for past difficulties emerged and were reframed as learning opportunities: *"anything of value..has been learned as a result of a failure"; "It's been a..fucked week..I'm grateful..because I've learned" (D:1; 2).* In discussing an experience where P's swan had been hurt, he stated: *"what's the positive opportunity here" (P:2); "if I hadn't gone through that..shit..I wouldn't be ready for the shit..now"; "the only way to grow is to bang your head" (P:2).* P expressed how the notion of death fosters opportunities for growth: *"had I been killed..I would have lost my human experience..it made me focus" (P1).* L expressed: *"the best you can do is to learn from that mistake, and go forward" (L:1).*

4.3.10 Stress as a Manageable Entity

Neither D, L nor P perceived stress as an overpowering factor. L's view has shifted from: *"stress played a detrimental role" (L:2),* towards stress as a motivating force: *"I strive on pressure..it pushes me" (L:2).* D felt that stress was a result of ineffective coping skills: *"people who can't handle where they're at" (D:2).* Reducing stress by adopting effective coping skills, may be employed. In responding with a sense of choice, P felt in control: *"I don't..need to be a victim of that" (P:1).* None related stress directly to HIV.

4.3.11 Sense of Loss

Focusing on their gains, respondents were not caught up by a sense of loss: For D: *"my unwillingness to father a child" (D:1)* was countered by his option of adoption. For L and P, losses pertained to sexual freedom: *"the independence of doing..what I wanted to..it's not a great loss..compared to the gains" (L:1).*

4.3.12 Changes Incurred

D, P and L seemed to revere the transformations evoked by their HIV positive status: *"change has been absolutely positive" (P:1); "I don't resist change, I..embrace it" (D:1).* Each respondent expressed a new found need for life: *"I went from self destruct..now I wanted life (D:1); "HIV has empowered me..I've become..dynamic, ALIVE..focused" (P:2).* D and L explored a new sense of choice and empowerment: *"I was in complete effect of my circumstances, I don't have to go into effect..anymore" (D:1); "before..I had no choices..I'm more informed" (L:2).* All respondents stated how they have let go of their fears: *"scared the shit out of me at one stage, it's not scary anymore" (P:2). "fear..always stood for..fuck everything and run..it can be..face everything and recover" (D:1).* Lucky expressed these words exactly. Each respondent seemed to feel free: *"I don't carry baggage anymore" (P:1); "I..enjoy a..sense of freedom" (L:1).* Related to freedom, D and P shifted from a materialistic focus: *"I've transcended three dimensional needs, wants or concerns" (P:1).* Each respondent's sense of connectedness towards the self and life seemed enhanced: *"I found.. interdependency" (D:1).* P explored his move from a *"self centred aspect, to a a universal aspect" (P:1)* and L stated: *"it has..reinforced..who I am" (L:1).* This in turn influenced how both D and P handle anger and interpersonal conflict: *"I would have committed murder before..now I take it..in my stride" (P:1;2); "would've thrown..my toys out of the cot..I've had to find other ways to vent" (D:1).* A theme of acceptance emerged: *"I didn't want to accept the reality of this virus..eventually you do" (L:2).* Where P explored living for today, D, in contrast, related that mentality to his past: *"drugs were..the..catalyst..to the live for today mentality..suddenly the..notion of purpose..came up" (D:1).* Although D communicated in a humorous manner, P made the point on comedy: *"in the last couple of years..a heightened sense of humour..fun" (P:1).*

4.3.13 Factors Facilitating the Healing Process

Mechanisms of coping are perceived as central to the respondents' current health status. Although discussed independently, these factors, which seem to facilitate stress management, interact in the healing process. Commonalties emerged as respondents explored a solution oriented, proactive coping style: *"the situation is fucked right now..let's look at some choices..what works for me..there's the solution" (D:1); "sort out a plan of action" (P:1).* Respondents regularly conveyed that they had let go of fear: *"there's no fear anymore" (P:1;2).* To attain this state of mind, D, L and P actively confronted their fears: *"you don't hide from it..bring it out" (D:1); "have a meeting with death" (L:1); "did the eulogy" (D:1); "settled my funeral" (P:1); "I get to grips with that reality then the fear..goes away" (L:1).* In actively facing their death, respondents seemed to awaken to living in the present: *"I don't entertain..thoughts of tomorrow" (P:1). "I only know NOW..this moment" (D:2).* Paradoxically, facing fears seemed to promote the resolving of future concerns: *"the dying part..take care of that..I have insurances..when I go..nobody is going to suffer" (P:1).* Similarly D explored how integrating elements of the past was essential: *"why do I need to reject an experience because it was painful, if I reject it, I'm rejecting part of myself..I embrace all of it" (D:1).* L and P couched this differently, for them dealing with past issues was about 'clearing baggage and letting go': *"make sure there are no..goggas hiding in the background,..this existence or previous..find those blocks and deal with them" (P:2).* This theme of 'dealing with unfinished business' is related to the process of releasing guilt, anger and moving forward: *"I needed to close that section in my life and create a new life" (D:1); "clear that guilt..against oneself..other people..dump your baggage..that..releases you" (P:1).* This fostered the theme of forgiveness and acceptance: *"forgive yourself" (L:2); "I have forgiven..I carry a free conscience"; "I don't carry anger" (P:1); "I don't carry guilt (L:2).* Thus, dealing with current, future

and past concerns seems to work in unison: *"You've got power now..let go of my past..acknowledge the future" (D:2).*

Related to 'letting go', themes of self expression and externalisation arose: *"ditch that..shit" (P1); "don't keep it inside"(L:1;2); "anger..I feel at a physical level..I eXpress at a physical level" (D:1).* L explored the notion of disclosure: *"disclosure is related to healing..you relieve yourself of..guilt and this secret you carry" (L:2).* This may relate to L revealing his identity in the study. Similarly, in dealing with difficulties, respondents: *"process this externally" (D:1),* via rituals, visualisation and exercise. These seem to promote a solution orientation: *"did this..dialogue..got the answers..if it wasn't with the virus it was with a dead friend" (D:1); "this ritual in the bath..I wash all the negative off..when I pull that plug..this crap's going out"; "go to gym..work it out" (P:1).* This invoked themes of relaxation: *"I play meditative..music..retreat from the world" (P:1),* which seem to contradict the active lives of the respondents: *"the only time you know you've been sleeping is when you wake up" (L:1); "live life to the full" (P:1).* Perhaps it is not about eliminating stress, but managing it: *"I strive on pressure..I survive stress, I don't avoid it" (L:2).*

Through dialogue and visualisation, respondents actively participated in the disease process. They seemed to be involved in a contractual relationship with the virus: *"I transported it outside my body..Mr HIV..Joe..I had this dialogue" (D:1); "we argue..we engage in discussions" (L:2); "I've spoken to it" (P:1); "I'm not going to fight you for my life..how can we coexist" (D:1); "we have a pact..it wants to live and I want to live" (P:1).* This mutual agreement elicits notions of equality and connectedness, intermittently contradicted by L's perception of war: *"it's about winning or losing the war" (L:2).* (see 4.3.6).

Themes of acceptance, honesty towards the 'self' and 'others', inner peace and spiritual trust arose, which rejected a sense of discord: *"deal with reality..don't create what it..should and ought to be.." (D:1); "accept the things I cannot change" (P:1); "We can never strive on pretense"; "the truth it sets you free" (L:2). "That's where you should be according to g-d" (P:2).* These relate to freedom and the process of letting go.

Where D explored embracing difficult parts of his life through a process of emotional healing: *"the..cathartic aspects..were so freeing for me"; "emotional pain..is quite exquisite" (D:1);* P and L, focused more on their positive explanatory style: *"just have a positive outlook" (L:2); "see a positive opportunity in everything that comes your way" (P:1;2).* All explored the significance of positive experiences: *"do what makes you happy" (D:1); "do more the things that make you feel good" (L:2).* P extended this to the aspect of laughter and self reinforcement: *"sixty percent of coping is learn to laugh.."; "I've come a long way" (P:2).* Positive emotions seemed related to the state of gratitude : *"be greatful: (P:2); "so grateful to be alive..the shit and the roses combined" (D:1); "I thank g-d for my life" (L:1).*

In perceiving problems as challenges, themes of resilience emerged: *"it's not a problem..how about a challenge" (D:1); "this is the challenge...how do I get through it" (P:1); "never quit" (D:1).* This stance seemed enhanced by the sense of clarity gained by all respondents: *"become very clear" (D:1).* For P, this clarity was enhanced by rituals: *"days of meditation and fasting to..get clarity" (P:2).* Gaining perspective appears to assist a prioritising process significant in restoring balance: *"distinguish between what is important and what is not"; "AIDS is not the only problem" (L:2).*

4.3.14 Feeling Empowered

Each respondent seemed to feel powerful in relation to themselves, the virus and others. Related to themes of interdependence and self belief, notions of equality emerged: For D, a sense of partnership evolved: *"it was..you are more important than me..no one..told me about..you AND me" (D:1).* Although L and P reflected this mutual power: *"I am equal to the task" (L:1); "win win solution" (P:1), 'coexist' (P:2; D:2)* was at times replaced with metaphors of war: *"it's the underdog..it's put me into a leadership position" (L:1); "If you fuck with me I will throw every bullet..at you and I will destroy you" (D:1).* All seemed to reject a victim position and explore their sense of entitlement, internal control and capacity to assume ownership: *"I have a right to be here" (P:1); "I have a right to survive" (D:1). "take control of your own experience"; "transfer the locus of control from exterior to interior" (D:1). "not looking to blame..this has happened to me because of me..I can undo it..I have that power" (P:1); "stop being a victim..take full responsibility for your own life" (D:1).* The word 'create' was regularly used by each respondent, evoking a theme of self determination: *"I created this shit" (D:1); "I create my own reality" (P:1;2).* Although entitlement is recognised, L cautions against over indulgence: *"take off this mentality of entitlement..what can the government do for me"; "I cannot depend on another person..other than myself" (L:2).* Thus empowerment is associated with independence. Themes of letting go, releasing fears, non discrimination and resolving issues, relate to a sense of power: *"because you've let go..you have the power"; "it's powerful not to be afraid" (P:1) "we were back in our power, 'cause nobody knew us" (D:1); "empowering..because there's no unfinished business" (P:2).* The process of learning appeared to enhance a sense of mental and physical control for all respondents: *"I was empowered..knew how my body functioned";"the more knowledge I get..the party ended for the virus" (L:1;2).* Thus empowerment was related to internal resources: *"empowerment..I'm not talking about..jobs (L:1).* For L, D and especially P, the sense of power extended into a spiritual realm, enhancing trust, a sense of belonging and reducing uncertainty: *"one doesn't see oneself as..this little entity, battling through life..you tap into this forc-e-e..call it g-d"; "I don't..fear..because..you're divinely created to handle..irrespective of experte-e-se" (P:1;2).*

4.3.15 Taking Action

All respondents emphasised the significance of 'doing': *"there's no point in having knowledge if it's not put into action"; "most importantly..action" (D:1); "I'm HIV positive..what do I do?" (L:1).* This theme was juxtaposed with others: 'Moving forward': *"do the work on myself..to get beyond where I was" (D;1);* 'Solution orientation': *"offer a solution" (L:2); "sort it out" (P:1).* 'Learning': *"accumulated knowledge..run with it" (P;2); "getting information..what I need to do" (L:2).* 'Participation': *"get involved in whatever you can" (P:2);* 'Empowerment': *"make a decision"; "the person who lives with the virus..equip themselves" (D:1);* 'Living fully': *"my day is taken up with living" (P:1);* 'Change': *"turned it all round" (P:1);* 'Separating one's beliefs from others': *"I turned what my doctor said was a..probability..into a possibility" (D:1);* 'Stress control': *"whatever stress comes..I DEAL with it";* 'Taking responsibility': *"kicks me into..a response mode" (P:1);* 'Resilience': *"I don't believe in backing down" (D:1);* 'Crisis as growth': *"when you're on the railway tracks..and someone is pointing out the train..WAKE UP" (D:1);* 'Reference memories': *"look at a time when you were the healthiest..reintroduce this..into your life" (P:2);* 'Externalisation': *"Act out" (D:1);* 'Confront fears': *"work your shit" (D:1);* 'Emotional healing': *"releasing..the BaggaGe" (P:2);* 'Thoughts': *"I can do anything I set my mind to" (D:1);* 'Individuality': *"do things..at their own pace" (L:1).* Taking action seemed to propel a shift from passivity and resignation towards self empowerment.

4.3.16 The Process of Becoming

As D voiced: *"I've abandoned me" (D:1),* so all respondents seemed to work through a process of self discovery: *"confronting who I am" (D:1).* All expressed an integrated identity, reflecting self acceptance and a sense of worth: *"here I am warts and all..that's okay" (P:1).* D and P focused on the holistic self: *"you're mulitdimensional..it's not just the physical level" (P:2).* Self acceptance, inner peace, humbleness, integrating the past and self cleansing accompanied this process: *"I'm..happy with where I am"; "I realise my..limitations" (P:1;2); "If I hadn't gone through that..I might be a..different person"; "guilt and shame are a..waste of time" (D:1); "wiping..the slate clean..releases you" (P:2).* L associated self acceptance with a sense of empowerment: *"self acceptance..puts people on that equal footing" (L:2);* whereas, *"feeling weak..you give..power to your opponent" (L:2).* Shifting from dependency, each respondent, despite cultural differences, separated himself from others: *"you own your shit and I'll own my shit" (D:2); "your opinion is not..what or who I am" (L:2).* Countering discrimination, self acceptance was related to the acceptance of others: *"I'm..okay with who I am..therefore I am okay with who you are" (D:1); "I've become..understanding of my own weaknesses..and other people's" (P:2).* An independent identity allowed the respondents to gain perspective: *"my body-y is HIV positive..I'm not" (D:1); "the virus is not me" (L:2).* For D and P, there was an interplay of dependence, independence and interdependence: *"I moved from co-dependent..to independent..the fuck you..then found..interdependency" (D:1); "my partner has his section..we have an inheriting section..there is his, his and theirs" (P:1).* Similarly, D and P explored how developing the 'self' relates to the process of giving: *"I can only give you when I have given me (D:1).* L seemed to shift from cultural traditions, which foster an external locus of self worth: *"culturally men..have more than one wife..it boosts your ego"; "I would like to spend more time with myself..loving myself" (L:1).* L explored disclosure as central to self acceptance: *"you're not telling..so you are not who you are" (L:2).*

4.3.17 A Sense of Belonging

The development of a separate identity was not an end in itself. In opposing individualism, self growth was enhanced through a sense of connectedness for all respondents: *"don't become narcissistic"; "you are..on your own..but..you..blend with everything..there's no separation" (P:1).* This theme adopted a spiritual tone of universal connectedness: *"we are all one" (D:1); "we are all mind..the collective unconscious"; "my connectedness to you..to g-d..to everything else on this planet" (D:1).* From a culture embedded in notions of Ubuntu, L explored this holistic stance: *"mankind was not made to live in a vacuum"; "I share my life" (L:1).* Herein, the individual remained crucial: *"you need..total self worth..before you can become selfless" (P2).* By rejecting dependency and promoting the individuality of others, each respondent explored the limits of connectedness: *"I don't have the right to tell you how..it's..up to you" (L:1).* Connectedness related to acceptance: *"I acknowledge the g-d in you..which removes judgements" (D:1).* P and L explored this theme in relation to empowerment: *"it's a feeling of belonging..you're not alone..it's a different power base"(P:2).* P illustrated the relationship between belonging and freedom: *"the more you open up..the freer you become" (P:1).* Where D felt: *"I have..a connection with..teenagers" (D:1);* L and P expressed a connection with younger children. A reciprocal relationship between learning and teaching, taking and giving emerged: *"the way to learn is to teach"; "you..give more and..become receptive to more" (P:1); "when you discuss..you enrich yourself" (L:2).* Connectedness may promote a process of mutual empowerment.

4.3.18 Social Support

D, P and L expressed difficulty in receiving support: *"I'm more my own support system" (P:2); "I'm not a person who allows myself to be supported..easily" (D:1).* D and L explored the effects of discrimination at micro and macro levels: *"social contacts cancelled me..no support at all" (D:1); "formal support is..not there" (L:2).* All reviewed how they chose instances of support: *"there are people I allow to support me" (D:1).* Social support linked to alleviating despair, loneliness, gaining perspective, letting go, a sense of purpose and relieving stress: *"when I feel down..I..go to a group of..people and talk to them" (L:2); "I..wasn't alone" (D:1); "they bring another dimension into my life" (L:2); "we..offload..talk..cry" (P:2); "you're going home to someone" (L:2); "a burden shared..is a burden halved" (P:2).* Related to themes of equality, D explored the disempowering process of sympathy: *"sympathy..says that I've got something you don't have" (D:2).* The word 'share', used by each respondent in exploring his preference for giving support, elicited notions of interdependence and reciprocity: *"I am a caregiver..because I take care of myself" (D:1); "as you give, you get back"; (P:2).* D explored the process of sharing as a form of support: *"I shared my longevity story..as a..hope" (D:1).* L reviewed how support may be found if people in need accept their status and let others in: *"you disclose..then other people can..care for you" (L:2).* Hence, individuals have a responsibility to gain support, thereby participating in their own healing.

4.3.19 Interpersonal and Environmental Influence - a Systemic Perspective

The occupations of D, L and P all involve educating others. They seemed to perceive their ability to manage HIV as a tool for influencing the coping capacity of others: *"they see how you cope, and it helps them" (L:2).* This theme related to the concept of reciprocity: *"my actions are creating reactions" (D:1); "a ripple effect"; "you're a catalyst for your own health and everybody else's" (P:2); "by exploring my way..you will establish your way" (D:1).* As role models they taught about: 'the self': *"I tell the kids..you're full of enzymes..but that's not you" (P:1);* 'action': *"I say make a decision now" (P:1);* 'responding': *"(mimicking voice) "you taught me this..what's the challenge here" (P:2);* 'choice': *"giving them options" (L:1);* 'power': *"being powerful empowers the next person" (L:2);* 'attitude': *"transfer..the positive outlook" (L:2);* 'acceptance': *"I tell them..it is okay..if they want to die" (L:1);* 'self efficacy': *"if you say this you can do..they stand up and..do (L:1);* 'responsibility': *"getting people to own their shit" (D: 2);* and 'living fully': *"I ask them not to waste time" (L:2).* D and P were influenced by role models: *"hearing other peoples' stories motivated me"; "I was in a rented tuxedo..until I had my own" (D:1).* Processes of modelling seem essential. L carried the concept of influence to macro social levels of formal support: *"influence decisions that government make" (L:1).* He explored how teaching others may influence cultural norms and prevention: *"aspects of our culture we..need to change"; "understand the dangers of being promiscuous" (L:1).*

4.3.20 Spirituality and Culture

D, L and P explored their faith in a superior power not linked to a specific religion: *"I'm not talking about g-d in the..christian..belief...just this incredible energy" (D:1); "there is this superior being" (L:2).* Spirituality related to a sense of power, equality and belonging: *"spirituality for me is my connectedness..I am not alone..g-d is..my co-pilot" (D:1).* For D and P, this seemed to move beyond belief towards spiritual trust: *"I don't have to believe, I know" (D:1); "I know that what I need..will come.." (P:2); "no coincidences" (D:1; P:2).* These beliefs may have prompted inner peace and the meaning of HIV: *"it comes for a reason.." (P:1).* For L: *"spirituality means something that I believe in..I believe in myself" (L:2),* yet for P, a philosophy of transcendence beyond this realm, seemed to dominate: *"you transcend the..third*

dimensional mentality..you're not subject to Newtonian laws" (P:1). This seemed to inhibit powerlessness as P was able to disconnect from the virus: *"my body is not me..it's..a vehicle I've borrowed" (P:1).* D and L explored cultural influences. D's: *'independent period" (D:1),* echoing the *"American model" (D:1),* was replaced with interdependence. In expressing the import of revealing the truth, L seemed to follow cultural norms: *"when you disclose..in the townships..you get together..it's not like in whites where there's privacy" (D:1).* Similarly L illustrated cultural deviation: *"in my culture people tend to hold on" (L:1).*

4.3.21 The Interconnection Between Mind, Body and Spirituality

All respondents perceived an interrelationship between the mind and body: *"the physical..is a result of the mental" (P:1); "how the mind channels..determines body" (P:2).* P and L viewed the mind as an internal resource: *"one can only be as strong as his mental capacity" (L:2); "you..are what you are because of your mind" (P:2).* D and P explored the power of beliefs in controlling one's experience: *"I believe it..then I see it" (D:1); "if they believe the expertise..it's gonna work" (P:1).* Reinforcing this, D discussed his belief in renewing his contract with the virus: *"last year I forgot..I came down with..pneumonia" (D:1).* D, L and P explored how emotions influence physical health: *"emotion..it's going to impact on the immune system"; "the emotional..is what started Bill dying" (D:1); "I..get..reoccuring thrush if I'm..stressed" (D:1).* This related to the coping mechanism of letting go: *"feel the anger, release..and move on" (D:1).* P and L discussed how attitudes and perspective influence health: *"lost friends..because of their outlook..the negative..becomes the dominant factor..that's what puts people into..coffins" (P:1).* A new theme of 'behaviour' emerged as integral to the relationship between mind and body: *"if you think good of yourself..you care for yourself" (L:2); "my thoughts..behaviour pattern..feelings..are all..part of the cure" (P:2).* Where L expressed how perception influences action: *"there would be no reason for countries to go to war if they thought they would be defeated" (L:2).* P and L explored the effects of action on health: *"indecision..that's vassilation that destroys you" (P:1).* P expanded the mind, body, behaviour interaction by introducing a spiritual dimension: *"we're a tripartite body..physical..spiritual..mental".* Within this interaction, health became a matter of choice: *"they allowed themselves to go..they accepted this as a death sentence" (P:1).*

4.3.22 Choices: Thoughts in Action

The discourse of each respondent captured themes of choice and active decision making. L, D and P recognised that their experience was subject to their 'choice' of response, which countered a sense of hopelessness: *"choice..very important..it gives you the..freedom" (L:2).* Choice seemed to permit a sense of future: *"you can run out of petrol, but you still have petrol" (L:2).* The respondents' reality of living or dying became an option: *"I had to decide if I wanted to live or die"; "when you decide to live you become..top dog" (L:1).* This concept relates to themes of creating positive experiences and self assertion: *"whatever I do..I REALLY want to do" (L:2).* Choice seemed to propel a solution orientation and a process of letting go: *"how do I move..so I can be out of this experience"; "What are my options here ?" (D:1).* Perhaps it's through 'choice' that a problem is framed as a challenge. Their belief in choice seemed to influence self development, the ability not to internalise societal discourse and their perceptions of change: *"I make up my own mind..I don't buy into other people's fears" (D:1); "the negative mentalities..I don't believe" (P:2); "people fear change..I changed that" (L:2).* Choice seemed to promote a sense of control: *"my state of good health..it's my choice"; "it won't change unless I allow it to" (P:1).* Lucky related the processes of learning and choosing: *"I make informed choices" (L:2).* For P, the notion of choice seemed heightened

by his spiritual beliefs: *"you chose this..sphere of life" (P:1).* It is my sense that 'choice' played a crucial role in fostering a subjective reality of empowerment and the capacity to assume responsibility.

4.3.23 Chosen Thoughts and Beliefs

The coping styles of D, L and P seemed underpinned by their core beliefs. Commonalities emerged: 'Action': *"turn the other cheek is a lot of crap" (P:1);* 'Hope': *"I believe miracles happen" (D:1)* 'Attitude':*"if I think bad thoughts..I'm going to experience..the negative" (D:1);* 'Resilience': *"problems are..vital" (P:2);* 'Separating the self': *"it's my..truth..not..your..truth" (D:1);* 'Control': *"my..reality..is based on my perception..my coping styles" (D:1);* 'Embracing Change': *"the journey from not knowing..is..the excitement" (L:2);* 'Gratitude': *"the gift of life" (L:2);* 'Sense of Power': *"expertise is..the recipient and their belief system" (P:2).* D and P seemed positive about future health: *"there is a probability that I will die..there is a possibility that I will die from HIV" (D:1).* L seemed less hopeful: *"there will come a time when I need..medication" (L:2).* This may reflect his dilemma of coexisting with or battling the virus.

4.3.24 Self Management of Health

All respondents assumed responsibility for their healing: *"to get well it's up to me..if I think it's curtains..I'll die..I am totally responsible" (P:2).* L, D and P, held adverse attitudes towards antiretroviral medication*: "drugs..in time will be resistant anyway" (L:1); "I used the stuff and was..unimpressed (D:1*); *"I've..a healthy disgust of medical things" (P:1).* Self management became a viable alternative: *"it's not about medication..discovering yourself is more powerful than..drugs" (L:2).* D explored how managing his health was a learned and individualised process: *"I've learnt to manage my health..I use my own management style..when I stop..my immune system goes haywire" (D:1).* D focused on being himself and monitoring his thoughts: *"If you're a size eleven, put on a size eleven"; "what I say to myself in the privacy of my..mind..I REALLY monitor"(D:1).* He entered the realm of self trust: *"I listen to my body.." (D:1).* This related to P's and L's perception of nurturing one's self: *"care for yourself" (L:1).* Neither D, L nor P, negated the role of the medical doctor. Where D couched this in themes of equality and empowerment: *"stop giving your power to the doctor..make your doctor your partner in..health" (D:1*), L and P expressed a need to shift responsibility, develop self belief and assume the power position: *"they put all the confidence in the doctor..TAKE that confidence and put it in yourself" (L:1).* P and D seemed to focus on the process of 'managing pressure' in which one makes conscious changes, cleanses the self, gains clarity and reconnects: *"stress is negative..in terms of this..virus I get things out"; "do something different..rid the baggage...now I am back in touch with who I am..and my..relationships" (D:1).* Subjective visualisations and writing letters to the virus, seemed crucial for all respondents to attain a sense of control: *"to reduce it to a controllable entity..visualise..according to your perception what this thing is..give it a face..reduced it to a tiny..thing"; "I wrote a letter..dear virus..we make a pact here" (P:1).*

4.3.25 Balance: Healing the Whole Self

As each respondent illustrated his current health status, themes of harmony emerged: *"inside..there is a tremendous inner peace"; "what I think..say..and do..are congruent with each other (D:1).* D used the concept of 'system balance' to illustrate how his immunity allows: *"infection to come in"; "it's about allowing the cycle..to have balance I've got to have the bad times too" (D:1).* Describing themselves as multifaceted beings, P and D assert self care at all levels: *"those three aspects of what makes you an entity.. the physical,*

mental, spirit ALL need feeding" (P:1); "it's about balance..spiritually..physically..emotionally" (D:1). L illustrated balance in cultural terms. In exploring the value self assertion, L expressed: *"I've been able to gel that in with this spirit of ubuntu (L:1).* P also reviewed balancing the self and being connected: *"people need you without exploiting you..give and receive..in equal quantities" (P:2).* In light of this, perhaps we can perceive how a crisis is transformed into growth, peace occurs in a context of forward movement and HIV is understood as a part of the 'self'. Balance may promote clarity and perspective.

4.3.26 Sharing Narrative

Both D and P regarded the research interview as a context in which processes of externalisation, self reinforcement, creating new perspectives and a sense of clarity were continued: *"when we started talking about it realising..there's stuff..I've never looked at" (D:2); "by talking about it to..uh person like yourself..you realise how far you've come..it helps you to focus..it's empowering" (P:2).* Thus the interview, as a context of social support and sharing, seemed to be a microcosm of the healing process.

4.3.27 Threats to Coping

Where D recognised: *"gifts in both" (D:1)* positive and negative *"sides of the spectrum" (D:1),* L and P recalled hindrances to coping. L explored how discrimination and cultural issues foster non-disclosure and a lack of formal support, hindering self acceptance: *"you feel ashamed of yourself" (L:2); "to get medication..that is the..war" (L:2).* Lack of knowledge provokes inaction: *"when a person has disclosed.. what now?" (L:2).* Lack of acceptance and inner peace inhibit a relaxation response: *"the more you deny.. you won't succeed"; "I couldn't sleep..all these conflicting thoughts" (L:2).* When leaving past issues unresolved: *"things of the past haunt you" (L:1).* P and L acknowledge: *"most of it has to do with guilt" (P:1).* Others may impact negatively: *"challenges to..health and..serenity..are emotionally based..involving close people" (P:2).* In exploring the impact of economic difficulties on stress levels, L eluded to the interaction of macro and micro factors on health. *"That's why it effects the poor..greatly"; "they worry..their stress levels are high"; "having money..gives you peace of mind" (L:2).*

4.3.28 Paradox

Throughout the narratives, dialectical patterns emerged. These seem to illustrate how the process of healing involves a sense of clarity in a context of complexity. D explored 'death and life': *"I'm prepared to die because I'm prepared for life" (D:1);* 'living in the present and the future': *"I only know now..I have long term plans" (D:1);* 'confronting finality and continuity': *"the..day I paid for my funeral, I..bought a house with a thirty year mortgage" (D:1).* P explored 'the isolated self and connectedness': *"selfish and selfless at the same time" (P:2);* 'being in control and letting go': *"you're..more in control..at the same time you're not in control" (P:2);* 'holism and individualism': *"pool all the different points of view..what can work for me" (P:1).* L explored 'power over and power under': *"I'm in control..the virus will take..control" (L:2).*

4.4. CONCLUSION

The *pursuit* of personal and social healing calls for us to open our minds to novel perspectives. "The only real voyage of discovery consists not in seeking new landscapes but in having new eyes" (Proust, cited in Miller, 1997: 9). Although these findings do not pretend to be absolute, conclusive or replicable, they may inform the artistic and philosophic spectrum of social work (Goldstein, 1991).

CHAPTER 5

SUMMARY OF MAIN FINDINGS, REVISED UNDERSTANDINGS, CONCLUSIONS AND RECOMMENDATIONS

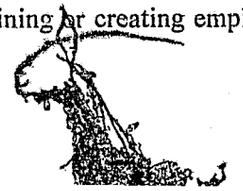
5.1 INTRODUCTION

This chapter sets out to summarise my research findings in relation to the aims of this study. Moreover, I revise my initial assumptions, draw conclusions, and in linking theory to practice, I hope to elicit applicable recommendations for health workers and further research.

5.2 SUMMARY OF MAIN FINDINGS

In light of the broad aim of this study, the respondents, who carry an HIV positive status, creatively authored their coping experiences and meanings attributed to disease resistance and progression. As the respondents explored their perceptions of HIV and healing through a narrative research design, gaps within the biomedical perspective of healing and disease were identified. Although differences emerged, common themes were presented. The following attempts to capture the core findings:

- **Rejection of traditional medical paradigms:** discourse couched in reductionist thought, linear cause and effect, disease orientation, negation of the whole person and practitioner expertise.
- **Belief in the capacity for self healing:** to assume responsibility for one's own health and recognise one's role in the health of others.
- **Healing as a holistic process:** to recognise the interplay of mental, spiritual and physiological processes and nurture this interrelated whole. To engage in a relationship with nature, a higher power, the 'self' and with others. To develop a sense of trust within these connections.
- **Immuno-supportive personal qualities:** a disgust at victimhood and dependent behaviour. A love for life and an appetite for discovery. An ability to extract learnings from past experiences and reframe a crisis as an invitation to growth. To flow with, as opposed to resisting change. To find the challenge in difficult events, explore options and seek solutions. To bring closure to uneasy issues, embrace reality and develop a sense of hope.
- **Creativity:** to respond to the seemingly irrational and incorporate complexity into one's life.
- **Proactive use of 'self':** develop clear perspectives, self awareness, acceptance and self care. Recognise one's rights and inner power. Learn as well as teach. Translate learnings into planned action and ask for support if needed.
- **Connect the micro and macro social levels of health:** to actively participate in governmental, political and cultural processes that influence health care.
- **The value of interpersonal narrative:** research interviews may be regarded as growth enriching processes which contribute to the healing journey.
- **Disease resistant behaviour influences social functioning:** in developing self belief, giving and receiving support, improving conflict management, ending cycles of dependency and embracing interdependency, intrapersonal and interpersonal relationships are enhanced. By gaining, maintaining or creating employment scenarios, one may contribute to economic productivity. In



utilising problem solving skills, seeking pleasure, connectedness and cognitively reapprasing events, environmental interactions may be enhanced.

- **Social discrimination and poverty may hinder disease resistance:** isolation and an inaccessibility of social resources foster disempowerment and disease progression.
- **Contextualising healing within a systems' interaction:** As other people became role models for the respondents, their coping styles were learnt. Similarly, each respondent is involved in an occupation which has the potential to influence others' thoughts, emotions and attitudes.

5.3 REVISED UNDERSTANDINGS AND CONCLUSIONS

5.3.1 Holistic Health: A Process

It appears that healing cannot be regarded as an isolated event. Rather, it is perceived as a process that involves the balancing of all system levels, namely people, their interpersonal and environmental realms. Two questions are posed: How do people interpret themselves in relation to their environment?; and how does the environment within which the person lives, affect the individual? It is only within this broader approach that we can comprehend an interplay of internal factors, namely perceptions, attitudes and emotions, with external factors involving economic, social, cultural and political processes. One's coping behaviour is a result of this interaction and directly influences health. Thus the individual system and its' sub-systems must be healthy.

Healing has not been illustrated as a black or white scenario. Rather, it seems to be a process involving contradictory and often mixed emotional, attitudinal and behavioural elements. Perhaps it is not about focusing on the confusion, so much as how balance and growth occur through the interplay of dialectical processes.

5.3.2 Intrapersonal Competency, Mulitidimensionality of 'Self' and Cognitive Reappraisal

As the 'self' is integrally related to the social context, the process of learning may be central in the development of self esteem. Yet, the 'self' need not succumb to negative societal or familial discourse. The individual has shown the capacity to monitor his own thoughts and recreate a positive internal environment. In fostering one's own reality, it seems as if components of the 'self' are made congruent.

Recognising the complexity of identity seems crucial to holistic healing. By acknowledging the 'self' as constituting physical, mental and spiritual components, HIV is perceived as only a part of the person. These other dimensions allow for a rational mode of thought to be complimented by that which cannot be reasoned. Mulitdimensionality seems to restore clarity, purpose and a sense of control.

In cognitively reframing that which seems dark into that which is light, factors mediating this process are vital. These may include a sense of belonging as opposed to being alone, and a feeling of being part of a spiritual whole, in which 'being in control' is balanced with faith. Moreover, developing an awareness of one's options and potential solutions may create a sense of freedom, eliminating feelings

of past, present and future entrapment. As inner peace develops and a proactive stance replaces passivity, that which is dark has the opportunity to transform.

5.3.3 Interpersonal Processes of Learning: Narrative and Social Support

Storytelling seems to involve more than merely communicating events between detached persons. It appears to benefit both the narrator and the listener. The story allows the teller to gain clarity, release negative thoughts, discover internal resources and rediscover his or her subjective reality. Further, it instils powerful learnings within the intersubjective context.

Although there seems to be a correlation between learning and action, there may be a disjuncture between the intellectualising process and the utilising of this knowledge. For system balance to be maintained and an active stance to occur, a cycle between knowledge and behaviour seems vital.

The receiving of social support is often framed as an action undertaken by those providing the support. Within the processes of self acceptance, humbleness and connectedness, lies the recognition of one's limits in satisfying the 'self'. The recipient assumes an active role in accepting others and reaching out to those whose support they seek. Furthermore, healing does not end with the recipient of support. As the respondents were largely providers of support, the giving process seems to be essential. Again, the connected 'self' is at play.

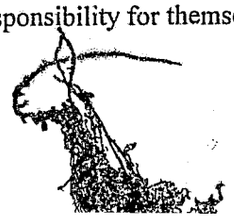
5.3.4 Healing and Disease: A Systemic Issue

As system levels interconnect, those who have learnt become teachers of others. The reciprocal process of learning and teaching endorses the notion of a 'ripple effect'. Thus the healing behaviours of one person may generate healing processes in a family or community. The opposite may apply, where victim orientated behaviours invoke an environment of hopelessness and disease progression.

The process of disclosure has been contested in this study. Two respondents disclosed their status publicly, while one respondent chose to retain his privacy. This conflict mirrors our national arena. Although disclosure seems to parallel healing processes of releasing negative emotions, promoting self acceptance and confronting reality, the dilemma remains. In a context which recognises 'distant healing' and the interplay between internal feelings and the reactions of others, discrimination as a reaction to disclosure may hinder disease progression. The process of releasing negative feelings may apply not only to those with HIV, but to the nation as a whole. National conscientisation may promote an environment conducive to healing.

5.3.5 Macro Level Participation

It is noted that taking action on an individual level is insufficient. As the process of healing is impacted on by governmental policy, participation in decision making is suggested. Similarly, healing is influenced by cultural norms. Reflective thinking and conscientisation become essential. People assume responsibility for themselves and learn to respond to their environment.



5.3.6 Partners in Health

The outcome of this research does not denote a denial of medical practice, but suggests a comprehensive approach that respects the balance of system functioning. As a comprehensive approach to healing regards the individual as integral to the process, expertise is shifted. In this way, healing is individualised, dependency is countered and collaboration is suggested.

5.4 RECOMMENDATIONS FOR SOCIAL WORK PRACTICE AND OTHER HEALTH CARE PROVIDERS

In light of the final aim of this study, I shall review the implications of these findings in the context of developmental social welfare.

5.4.1 Community Education

As educators, social workers may conscientise local communities and health care workers with regards to comprehensive approaches to health. Education around holistic reasoning may help communities tap multidimensional resources. Such an awareness, linked to social work values of participation and wholeness, may assist society to recognise that health is the responsibility of all.

5.4.2 Environmental Intervention

As macro level policy influences the attitudes of others and one's own thoughts, and socio economic issues of poverty influence coping behaviour, practitioners should involve themselves in policy making processes, social development and educate communities on the effects of discrimination. In developing this environmental emphasis, practitioners may indirectly influence disease resistance.

5.4.3 Practitioner Intervention with Extended Systems

Within systems interaction, the family and caregivers may have a direct role in disease progression. Perhaps social workers should work with HIV positive clients, people with AIDS and their respective care givers. In using the mechanisms that moderate stress; depression, hopelessness and anxiety at all system levels my be reduced. This directly benefits healing.

5.4.4 Facilitate a Growth Enhancing Environment

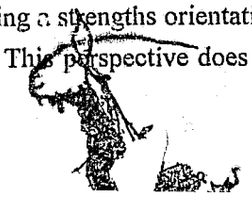
Although an 'all in the same boat' phenomenon is espoused in group work literature (Corey, 1997), practitioners may shift forms of social support that foster victimhood, towards those that promote acceptance, support and change.

5.4.5 Encourage Individualised Spiritual Growth

Embracing the values of diversity and individuality, perhaps practitioners should begin their own spiritual journey and create the space for clients to explore *their own* spirituality.

5.4.6 Work Within a Competency Orientation on Individual, Group and Community Levels

In adopting a strengths orientation to practice, social work intervention may reflect the holistic healing journey. This perspective does not deny a reality of hardship, but reviews difficulties in a context of



potential resources. It rejects a linear view of causality and promotes client competency at all levels. Based on literature by Whittaker and Tracy (1989), Egan (1994), Saleeby (1996) and Mallucio (1981), the following form of intervention is recommended:

- Practitioners need to incorporate notions of healing and change into their discourse on HIV. By negating the possibility of mental, physical and spiritual influences on immuno-enhancement, practitioners minimise the power of their client. Locked into a paradigm of pathology, the client is rendered a victim. The nature of this interaction may impact on disease progression.
- Enhance client competency on an intrapersonal level. Assist the client to work through emotional difficulties, to cognitively restructure faulty perceptions, create functional self statements and find positive reference memories. Negative beliefs should be identified and replaced with positive affirmations. Anger management, relaxation, meditation and visualisation techniques should be developed.
- Develop interpersonal competency. Assist the client to develop social skills to form and maintain relationships, to give and receive social support and deal with interpersonal conflict and stigma.
- Enhance environmental competency. Develop clients' skills to respond to and manage their environment. This may facilitate self responsibility and buffer perceptions of stress.
- The process of assessment should become a search for strengths within and around the client, thereby shifting the client from a sense of loss, towards possibility.
- The helping relationship may act as a prototype of active involvement and relatedness. Clients, given the opportunity to practice self determination via participatory decision making, strengthen their awareness of interdependence. In adopting a position of control, dependency and a victim stance is countered.
- As a tool of social support and acceptance, the relationship should create a space that counters secrecy, stigma, guilt, isolation and permits clients to confront their fears. This reduces the risk of further psychological, emotional and physical illness.
- Listening to the client's narrative, his or her perceptions of HIV and starting where the client is, promotes the value of subjectivity, self development and renders healing as an individualised process. This inhibits the infiltration of oppression within the healing process.
- The helping environment should enable clients to recreate their stories, by reviewing past events and consciously transforming past decisions which influence their current functioning. This permits the development of a productive version of their world and new possibilities in thinking, feeling and acting. This corresponds to the constructivist theory proposed by Fook (1996).
- As clients' options and past coping mechanisms are recognised and their future plans negotiated, the relationship becomes characterised by a process of learning and enhances a survivor mentality. Stress management may balance concerns with strengths.
- Goal identification propels a future orientation and a sense of purpose. Creativity within this exploration elicits optimism, which counters feelings of entrapment and mobilises hope. Thus the worker-client interaction develops a 'life orientation', as opposed to drowning in themes of death.

- Although the practitioner adopts an educative role of information giving, strategies centre on developing insight and action. Externalisation through role play, dialogue with, and writing letters to the virus, may endorse inner resources. Cognition become the clients' strength for change.

As clients are enabled to involve themselves in a collaborative partnership, they may transform their perceptions of their 'self' and their world. Moreover, they may change their response to difficulties and assume responsibility for their healing process. Hence, through the social interactions inherent in a working relationship, disease progression may be hindered.

5.4.7 Recommendations for Further Research

This study developed findings from a snapshot of the lives of three HIV positive men. It would be useful to repeat this study in more depth, using a larger sample inclusive of HIV positive women and participants of a different age, culture, race and educational level. Moreover, updated research would need to be reviewed. In utilising a grounded theory paradigm, a model for the HIV and AIDS field may be developed, thereby facilitating interactive co-operation in healing.

In a South African context rife with poverty and violence, where basic needs seem to override needs of spiritual growth and self development, further research may seek to understand how people in a more disadvantaged context experience HIV and AIDS. A study that aims to explore self generated healing in these impoverished contexts, and whether the mechanisms used in the healing journey complement those discussed in this study, may contribute hugely to our current social and economic realm.

5.5 CLOSING

As AIDS forces us to face the limits of our present systems, it is my prayer that we open our hearts and minds to the complex interactions that mediate internal regulation. As we admit that "what we observe is not nature itself, but nature exposed to our method of questioning" (Heisenberg, cited in Miller, 1997: 307), we realise how we have negated the interweavings of endless rhythms and created cycles of disempowerment. Hence, we lose the ability to think in terms of a greater whole, we sell our souls to the doctor who assumes he is the only one who may restore health, and we limit human beings, individual and collective, from becoming agents of their own development (Miller, 1997).

Social work is essentially about the preservation and enhancement of the total person. Lodged in Western paradigms that discount multiple ways of knowing, the profession may blind itself to the mysteries of being (Tracy, 1987; Sacco, 1996). Yet, as we tap into the mind-body-spiritual connection, it becomes evident that; "All things are connected.. whatever befalls the earth befalls the sons of the earth.. Man did not weave the web of life. He is merely a strand in it. Whatever he does to the web, he does to himself" (Chief Seattle, cited in Sacco, 1996: 35).

APPENDIX A

LETTER TO RESPONDENTS

Dear xxxx,

This letter serves to outline the primary incentive for the research project undertaken by Hayley Katz and various aspects of your potential involvement.

Our world is constituted by a range of people who are inflicted with diverse illnesses characterised by overactive, dysregular or under active immune systems. However, it is the latter with which this research is concerned. HIV/AIDS is without a doubt the most formidable health problem facing South Africa at present. The World Health Organisation has stated that AIDS will be the cause of 10 million orphans world-wide by the year 2000, 90 percent of which will be in Africa. Despite this, our government has closed research hospitals and has made huge reductions with regards to social services. Implicit within this, is the notion of 'self reliance in healing'. As such, our community is posed with two major challenges; firstly, to prevent the further spread of this disease and secondly, to understand the dynamics involved in developing 'disease resistance'.

It is with these factors in mind that I have a deep quest to understand how individuals like yourself, facing great obstacles to wellness are managing your illness, continuing to live your lives and contribute to your surrounding communities. This research project will take on a qualitative stance. This means that it shall aim to understand your unique and subjective experience with the disease in all realms. It is not about judgement, right or wrong, it is simply an exploration to further our understanding of the human potential and possibly to transform our dominant and narrow conceptions of healing. In this way the research does not aim to be foreign or inaccessible to others in our community. Rather to allow them to identify with your experience and possibly empower themselves by transforming their sense of victim hood. For this reason, this form of research is not about what I shall be doing to you, but what we shall be achieving together.

In order to elicit this meaningful knowledge and experience I am attempting to create a sample of three people who are diagnosed as HIV positive, continuing to live meaningful lives and growing emotionally and spiritually. I will need to spend about two hours with each individual person. In this time, I shall pose broad guiding questions to be discussed. The duration of each session may be half an hour to one hour. This will be clarified at a later stage. The times will be mutually decided on.

Information elicited in the interview may be considered sensitive to both you and myself. For this reason I undertake to respect this by holding the information in confidence. Firstly, the information that will be documented will only be done so with your informed consent. You may go through the interview transcript and edit the document so you are comfortable and satisfied with what is printed. Secondly, any identifying detail e.g. your name, may be changed in the document. If you have any other requests for confidentiality please feel free to discuss them with me. Please remember that the choice to partake is yours.

I have a deep respect for those people diagnosed as HIV positive and taking proactive steps to maintain their health. It is my hope that through this research together, we shall voice the experiences of three people and in so doing broaden the choices and hopes of many.

Best Regards
Hayley Katz
Social Work 1V student, University of Witwatersrand.

APPENDIX B

INTERVIEW GUIDE FOR INDIVIDUAL NARRATIVE INTERVIEWS

1. Introduction

I would like to thank you so much for giving of your time and energy to be a participant of this research project. The letter I sent to you outlined the motivation and purpose of this study - do you have any questions in regard to the content of the letter ?

With reference to this I would like to add, that as a student member of a helping profession it has come to my attention how many people when faced with health concerns, seem to rely purely on the opinions and medical actions of doctors and 'experts' alike, feeling as if they have no control over the healing process. It is with this in mind that I would like to get a better understanding of what living with an HIV-status means to you and how you are managing this status in continuing to live your life, to grow and seek fulfilment.

So from the start let me say, it is YOUR unique, personal experience that is of value to this study. It is not a question of what is considered medically right or wrong, what is significant are your own thoughts and feelings. It is my hope that stories like yours may assist others in managing their challenges and status.

For this reason I have chosen the kind of research, that gives voice to your experience and feelings that simply cannot be measured. I shall be asking five broad questions regarding areas I would like us to talk around, three of which are detailed areas of exploration. Within these there are specific questions based on my understanding of managing an HIV-status according to various readings and courses I have done. These questions may act as a guide in relation to your story. This is our first interview and it will proceed for about an hour. As explained in the letter, we will meet for another interview to clarify and further explore your story.

Would you mind if the interview is tape-recorded? This will assist me in analysing your information and comparing it with the two other participants in the study. Your name will not be used in the final report, unless this is your choice. If not, you may like to make up a name for yourself. I would like to encourage you to read the research report in order that you feel confident regarding confidentiality. Do you have any questions or concerns at this point ?

To start off our interview, I will be asking you basic questions about yourself. These will be used to help me understand your situation better, as well as to compare your experience to the other participants.

2. IDENTIFYING INFORMATION:

(Any information in parentheses is limited to the interviewer only)

2.1 What is your gender?

2.2 What is your race ?

2.3 What name would you like to call yourself in the study?

2.4 What is your present age?

2.5 What kind of work do you do presently? How long have you been engaged in this form of work?

2.6 What is your home language ?

2.7 What culture/community do you identify with ?

2.8 How would you describe your family structure ? (open, closed, nuclear, extended).

2.9 Are you presently involved in an intimate relationship? If yes, for how long have you been involved in this relationship? If no, when did your past relationship end ?

2.10 How long have you known that you have been HIV positive ?

2.11 What stage of HIV would you define yourself in?

2.12 Do you know your current T cell count/viral load? If so, have there been any changes in this regard?

2.13 Are you or were you on any antiretroviral medication? If so, what and for how long? Are you covered by medical aid or other forms of insurance?

3. MAIN BODY OF INTERVIEW: The focus will now shift towards your story.

3.1. Broad Topic to be covered

It is my understanding that a number of diverse **changes** are experienced after learning you are carrying the HIV virus. Perhaps you could share with me YOUR experience of living with HIV and the changes and subsequent impact it has had on YOUR life and others.

Probing Possibilities - to be utilised if the broad topic is not fully explored.

- *What were your immediate impressions after being diagnosed as HIV positive? How have these perceptions changed:*
  What did HIV initially mean for you. What are your current perceptions of the meaning 'HIV' ?
- *Do you feel you are in a type of relationship with the HIV virus ? (explain fully).*
  In this regard, how has your sense of identity shifted in relation to your current status ?
- *What impact has your philosophy of life, prior life experiences and decisions had on living with HIV ?*
- *How has becoming HIV positive impacted on your quality of life?*
- *What changes has your HIV-status provoked, both in terms of losses AND areas of growth ?*

3.2. Broad Topic to be covered

Since you discovered you were HIV positive it is my understanding that you have your own forms of **coping** and in a sense participating in your own healing. If you were to share your story with others who are struggling with their HIV-status, what key **factors** would you say have helped you to **cope** with your situation, maintain your level of health and prevent HIV from progressing further ?

Probing Possibilities - to be utilised if the broad topic is not fully explored.

(All factors noted in parentheses are limited to the interviewer only)

- *What do you understand by "participating in your own healing" ?*
  Has this belief assisted you, if so how ?
- *What did 'healing' mean for you initially and what are your current perceptions of the meaning 'to heal' ?*
- *How do you generally perceive and deal with 'change' that you experience in your life ?*
- *How are you experiencing and coping with stress since you became HIV positive ?*
- *What is your perception of your healing environment and types of support given ?:*
  Formal support: (medical services; financial/legal aids, cultural beliefs and legislation).
  Informal social support systems: (family, friends, others with HIV-status).
- *What factors do you perceive threaten your coping strategy or block your healing process with regard to:*
  Factors inside of yourself.
  Factors within your environment.
- *What factors do you feel have facilitated your healing and living process with reference to:*
  Factors inside of yourself.
  Factors within your environment
- *Who do you perceive are the experts in the process of healing and living with HIV.*

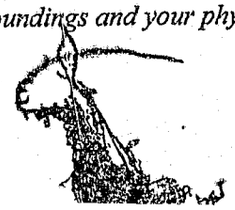
3.3. Broad Topic to be covered

According to the readings I have done, there seems to be a shift whereby people look beyond drug therapy and biological factors in shaping their health outcome. In your own experience, how have you found that your thoughts, feelings, spirituality and social interactions have impacted on your immune system functioning ?

Probing Possibilities - to be utilised if the broad topic is not fully explored.

(All factors noted in parentheses are limited to the interviewer only).

- *What are your views regarding the relationship between your thinking/attitudes, your social surroundings and your physical status ?*



- *How do you think your present coping style, thoughts and feelings may be impacting on your sense of who you are / would like to become and your interaction with others ?*

- *What have been the attitudinal, emotional, behavioural or spiritual changes that your coping behaviour has possibly triggered in others of your community ? (family members, friends, work colleagues, religious associates or others with HIV/AIDS)*

3.4. Broad Topic to be covered

I was wondering if there are any other issues you feel you would like to discuss in relation to having an HIV status and continuing to live and grow in life ?

3.5. Broad Topic to be covered

Perhaps you could share how it felt for you to discuss your experience of living and managing your HIV-status during our time together today ?

Once Again, thank you very much for giving so much of yourself during this study.

APPENDIX C

Part 1
David - Narrative Interview - 1 of 2

I: Okay.. first some identifying information.. very basic um.. you've decided you will be call-led your name in the study.. Your present age ?

D: Present age is thirty eight.

I: Thirty Eight... okay .h what kind of work do you do at the moment ?

D: It's a combination of things. I uh. it's all training -ing based um I run several businesses.. and. the theme has always been around training empowering people.. essentially say-ing transfer that locus of control from exterior to interior.. and it's not it's you can. it's this is how you actually do it.. all right. so we're very focused on action. we're very focused on too-oo-ls I'm not interested in some intellectual wank about how you can live your life alla Mike Lipkin stuff. (smiling) [

I: [((smiling gently with respondent))

D: show me HO-O-W.. that's what I'm interested in we're in the show me how stuff

I: okay

D: So that's kind of what we do a-and it's in the f, area of AIDS. it's in the area spec- specifically w-women and teenagers and children with AIDS I'm not really interested in the male population per say.. .hh ummm.. it's in the area of empowerment for corporations empowerment we work for schools.. admin. departments .hh we also are change-agents so-o if a company is about to go through transformation .h they will bring me in and my team.. Neil myself Gil and the rest of us .hh and say to us these are the issues we have. this is where we need to get to what do you recommend to help the process as smoothly as possible. not necessarily as pai-ai nless as possible but as smooth as possible.

I: efficient ?

D: Y - Umm not even efficient. we can we allow lot of margin for error and stuff like that. .hh'cause it's a learning curve for them as it is for us so we facilitate a process,

I: Uh huh .. umm how long have you been doing this ?

D: I've been doing this for.. um ..specifically for five and a half years going on six.. prior to that I was a death and dying therapist in California working with people who were dying.. .hh umm and also the families and all the associated issues surrounding that.. and prior to that I was a chef while I was learning to become a.. death and dying therapist.. shoe salesman, I've been a lot of things (Loud laughing)

I: ((Laughing with respondent))

D: As a chef I had no training I bullshitted my way into the job somehow I got it and I pulled off a miracle so it was like.. grab it out of a hat scenario

I: Are you serious ?

D: Ya.. wound up working for all the rich and famous in America. it was fabulous

I: I see all the recipe books in the kitchen.. that's you - (laughing)

D: (Overlapping) yeah, that's how I learned how to cook (laughing).. I worked in uh.. restaurant in uh.. in Palm Beach Florida and uh.. it was a five star restaurant, I had no work I was a cocaine addict I was-s like - really down in my life .hh came from being an Auckland pest control man.. you know there's me the Auckland me.. yeah like right.. .hh and uh they advertised this job as an assistant chef.. and I went for the job I got fired after two weeks 'cause I was completely useless =

I: = (laughing)

D: botched up everything I touched an-n-d saw a job in the newspaper for a private chef.. applied for the job.. got it and never looked back.. eight years it was fabulous..

I: (Overlapping) my word..

D: it was the most amazing career.. and then the whole HIV thing.. in.. while I was doing that I was still working HIV etcetera.. but I'm getting side tracked so..

I: Okay..

D: You have to keep me focused cause I can ramble..

I: I'll just hold you..

D: okay great..

I: Home language English ?

D: Correct

I: What culture or community would you-ou say you identify with ?

D: Oh g-d I could give you some esoteric bullshit.. but I won't, umm I really don't identify with any culture.. per say, I-I.. from a religious perspective or spiritual leaning I would say it's more towards judaism-m than it is to anything else.. from, a moral perspective I don't have any (laughing) so I can't really [hinch ?] myself there ..raised Anglican.. not terribly religious .hh and yet I was reading 'Conversations with G-d' and I realised.. just how strong my indoctrination was even though I wasn't raised .hh in a Christain-n fundamentalist background, there were strong Christian ethics throughout all of it, I just didn't recognise it.. um adopted child, birth mother afrikaanse.. birth father no concept, adopted by two English-sh upper class.. pommy's.. and raised by them in Africa..

I: (pause) how would you describe.. again completely yours.. your family structure... today ?

D: Today ? and are you talking about this family or-r

I: Whichever one you identifying with..

D: I have two.. primary people in my life.. u-.. I have a male lover. Neil and a friend in Neil of course.. and then I hav-ve a female lover but in a non-s-xual sense with Gil..=

I: = Uhh.

D: = so-o I have, a female and a male energy, because I I feel like I am pretty balanced in both of those departments and I need input from both of those departments.. I find the male energy, whilst I find it sexually appealing.. is also a side of me that is like I - I <u>really</u> can't handle raw energy.. other than than for me as a sex thing - as a sex object .hh I would much rather be with a women and spend my energy exchanging with her..-

I: (Overlapping) and you're getting both..

D: 'cause.. a-and I am I'm getting both.. and it's interesting cause I've always been that way since I was a child.. always had a-a male lover and a female best friend.. female lover for the want of a better word.. just a non-sexual relationship.. physical, but non-sexual,

I: Yes..any other family that you think you would..

D: mother and a father.. umm I had a sister who lives in Johannesburg, we were estranged for about, fifteen years because of my HIV status she just could not get her head around that.. umm mother and father I love and respect they're my mother and father.. umm as people.. you can take them or leave them to be honest with you, you know it's just like I.. they stay in their business and I stay in my business and then we have our business between us.. and the business between us is-s, I call home once or twice a week we chit chat and ha ha ha.. I get to hear all the moans and the pains and the groans and the martyr syndrome cuck.. I unhook and say yes uh huh.. okay love you buy I'll talk to you during the week.. click... a-and I don't.. my family is not involved in my life and I, that is my choice, they would love to be more involved I won't let them...

I: ... David.. hhh how long have you known you've been HIV positive ?

D: <u>March</u> the thirteenth 1983.. sixteen years and counting..

I: .. Okay, umm.. the stage of HIV that you would identify yourself in .. how would you.. ?

D: .. Oh we'll I'm definitely not asymptomatic - I am definitely asymptomatic.. I'm not symptomatic at all.. I do have.. it, it's weird cause my immune system.. it's the the normal T-cell range I'm well within normal range I'm usually around a thousand.. =

I: = Oh really

D: = viral load is practically non-existent, it's five thousand below so it's almost non-detectable.. when I was diagnosed my immune system the T-cell count was at three sixty two so my immune system had been severely compromised, I had more symptomology <u>then</u> then I do today.. I still get things like reoccurring thrush if I'm in a real stressed out situation.. I will get, a little bit of hairy xxxxx once again when I'm stressed out.. It's interesting 'cause I've learnt how to manage my health when I stop managing my health my immune system goes hay wire and things manifest.. which I've always seen as okay.. g-ds trying to give you a bit of a message here.. slow down a bit otherwise he's going to slow you down permanently and that wouldn't work for me =

I: = Uh huh

D: = I've got too many things to do still.. so I use, I use. my own management style of my system and there are times that I allow myself to let go.. to let my body go through a purging thing um.. I get reoccurring pneumonia twice a year.. or at least that's been the way it has been for sixteen years .hh doesn't

necessarily mean it's going to repeat itself.. whenever I'm in a large crowd situation if there is something floating around I'll pick it up.. so my immune system is completely in tact and yet there are parts of it that will allow infection to come in.. kind of weird..

I: Is that the strength -

D: (Overlapping) I think it's about allowing the season.. allowing the cycle.. for me-e.. that's my interpretation of it. it's like I've got to have the good times and in order to have that balance I've got to have the bad times too.. you don't kno-o-ow.. the smell of the rose until you've worked with manure to get the rose to where it goes to.. that kind of stuff - lemons and lemonade.

I: Um.. are you are any-y-y medication ?

D: NOTHING.. pot - dagga that's it.. I did. I was in the original trials of AZT at (xxx) University back in ni-i-i-neteen eighty six when they first started using AZT they pulled it off the shelves.. I used the si for about four months and was completely unimpressed, my myosytis got worse I - I had energy el which I never had before, I'm a very active person ummm.. and I just.. the stuff didn't work for me I literally threw it out the window... I often.. jokingly say (mimicking voice) "Oh.. I'll never go on anti-retrovirals, I don't need meds blah blah blah.. I've never bee-ee-n, in a position where my health has warran-n-ted at the same time as being medication to help it.. so I was sick and there was NOTHING.. I got well and there was a whole bunch of stuff, so-o... uh, once again I think.. you know.. g-d.. there's no co-incidence (laughing).. there's no co-incidence.

I: Umm... David I am going to move now more towards your story..

D: All right

I: Umm... It's my understanding that a number of diverse changes occur after learning you are carrying the HIV virus.. perhaps you could share with me your experience of living with HIV.. the subsequent changes a-and impact that it's had on your life.. and others.

D: That's broad..

I: Broad

D: Okay.. it was interesting 'cause when I was diagnosed the disease was not called HIV.. all right let let me backtrack in nineteen eighty two I was in Iowa I was with my first lover Tommy we had been together for about four and a half years.. a very turbulent um.. very fucked up.. dysfunctional relationship.. can I swear (whispering)?

I: Ye-e-s ...

D: Oh okay cool

I: Be you

D: I am me okay, I 'm me.. (laughing).. so-o-o we were living in Iowa and I came down with-th.. what appeared to be.. this was in the August of eighty two.. appeared to be mono-like symptoms.. all right I thought well maybe.. cause I had been a bit of a slut in my day.. a-and.. um, when when it happened figured it was just glandular fever or something on those lines and the symptoms lasted.. probably about six to seven weeks and I was uh. I wouldn't say I was deathly ill.. but I wouldn't say I was a happy little camper. I was not feeling good.. the symptoms then went away.. In January of eighty three I moved back to Las Vegas where I has originally, when I first arrived in the states that s where I lived.. um moved back to Las Vegas and it was in Ma-arch of that year that a friend of mine called Michael got sick.. and we all thought it was like a really bad cold an-n-nd the cold never went away, actually it started in January.. when we first got back.. .hh Michael was very flue-e-e and stuff and he went through this whole process an-n-n-d on the tenth of March, he uh, on the ninth of March he had to go the hospital cause he simply couldn't breathe anymore.. .hh and he was wasting away and getting very thin what we know now of course as classic AIDS.. .hh um .. he died on the tenth of March.. his docto was also my doctor... his lover and I were best friends and.. the doctor-r told us about this thing called GRIDS which they were seeing in San Francisco New York all those kinds of places. but in very isolated, b - but specifically the gay community.. .hh the minute he said this - like fuck-ck hhhh.. okay.. all this stuff sounds very familiar to me.. the night sweats, the diarrhoea, the weight loss the chronic fatigue blah blah blah. all this stuff was there and the weight loss in that point in time I was down.. .hh I weigh eighty eigh - eighty nine kilograms on a good day.. .hh I think I was down to about sixty three. sixty four.. =

I: = Shuh..

D: so I was an emaciated thing ((pulled facial expression to display this look)).. I was also a cocaine addict. so I don't know which one it was.. uh truth be known.. ummm, he told me about the symptoms and I said (mimicking voice) "well I think I've got it" and Bill said the same thing. he was Michael's

lover.. umm and he thought he had it too.. he said (mimicking voice) "well I can't check you for it, 'cause there's no disease.. what I can do is I can look to see how your immune system was working... .hh so they did an immune (xxx), which they rushed through and within three days we got the results, thirteenth of March my birthday.. .hh twenty second.. come to the doctors office and he says (mimicking voice) "I don't know whether you have it.. all right.. but what I can tell you is your immune system is severely impaired.. every indication points to the fact that you have this thing called GRIDS, so I'm going to call it GRIDS.. .hh". And I said to him (mimicking voice) " what is it ?" and he said (mimicking voice) "It's.. we don't know a whole hell of a lot about it.. we know it's a disease.. we know it's sexuall.. we <u>think</u> it's sexually transmitted.. .hh and we know there's a strong.. what we've <u>see-ee-n</u>.. there are people who get it and then they die"... an-n-n-d interestingly ((light laugh)) enough he said to me (mimicking voice) "you've probably got about six months to a year left t- to live.. my advice to you is go home and get your affairs in order.. and please never come back to my office again"

I: Hmm

D: And that was the first time I experienced it... the the prejudice.. and and and m-my truth today is.. .hh had I been on the other side of the fence I probably would have dealt with it in exactly the same way.. so-o when I when I make comments like this I'm not judging what they did.. I <u>really</u> understand, and probably would have done the same thing myself. and that's not this forgiving hari krishna cuck.. that's really how I feel, .hh.... the-e-e.. Bill-l who was Michael's lover was a lieutenant colonel in the military.. they had been trying seventeen years at that point.. they had been try-y-ing to nail him for being a homosexual.. because the American m-military like are <u>major</u> homophobes.. so they were trying to nail him for being a homosexual... somebody on the base.. h rd through.. no hang on a second.. I'm getting confused.. Bill. when Michael died and Bill found ou e had this thing called GRIDS. he went to the base commander.. he was a surgeon, he went to the base commander and he said to them (mimicking voice) "I don't know what's happening.. I don't know if I'm even talking out of turn here" and he shared with them what his story was he didn't get into the homosexuality stuff.. .hh the military took that and turned it into a homosexual issue, so they started a - a secret investigation against him.. in the mea-ea-n time Michael's death was the first recorded death in - on the West coast other than San Fransisco so the Los Vegas connection was now suddenly made.. here's patient zero Las Vegas.. .hh made Michael out to be a complete slut.. at the same ti-i-me divulged Bill's status and my status as well. so it hit the newspapers in one evening.. this is like the the eighteenth or the nineteenth of .. March.. .hhh (sigh).. so immediately the phone calls started.. the nasty phone-calls the bomb threats the bricks through the windows, somebody tried to poison the Snauzers.. Bill had some uh two Snauzers.. Bills trying to deal with the loss of Michael and that whole thing umm.. a -a -a <u>really horrible</u> horrible period.. talk about the dark night of the soul..I mean you have <u>no concept</u> what that looked like.. instantaneously all of my social contacts cancelled me out completely.. there was no-o-o support at all.. and I didn't. I - I actually was so young and so - stupid I didn't know what to do.. so do another line. you know everything will be okay.. do another line fuck your brains out and dance to the early hours of the morning and everything's gonna be okay.. and the song that comes up for me at that point in time is that song.. I don't know if you've ever heard it.. if you haven't I will play it for you later.. it's called forget the future live for today.. and that sort of became my theme. and my my life has been done with music... and there's a song for everything. (laughing).. =

I: = ((Laughing with respondent))

D: umm.. the song that I did on the way home from the doctors office was uh.. a song from the Best Little Whore House in Texas called Girl you're a Women Now.. (laughing) and I was crying and looking in the rear view mirror.. the tears are strea-ea-ea-ming down my face.. didn't know what any of this shit meant.. anyway I'm getting sss derailed again.. once it hit the media.. it was like.. w-we were finished in in Las Vegas there was no leg which we could stand on.. I say we because Bill and I.. Tom and I were in the throws of separating that was already a done deal.. Bill and I I think latched onto one another because. he knew he had this disease.. I knew I had this disease and everybody else had dropped us.. so-o a relationship <u>had</u> to happen and it did happen that was uh an amazing experience seven very wonderful years of my life.. uh.. we became each other's support network and I I've never been one to be a down person.. granted I tried to commit suicide dozens of times in my life.. but that's always an irrational - spur - of the moment (clapping) (mimicking voice) "UH FUCK IT I'M OUT OF HERE" you know.. there's very little lead up to-o months of depression and sitting around listening to Judy Garland with candles burning.. none of that crap.. =

I: = Uh huh

D: Umm. I've always had that ability to <u>fi-i-i-nd</u> it som-m-ewhere and if I was to get a lemon I make lemonade.. somehow I am going to make something from this lemon.. so I've don-n-e.. I did that..it's a

very strong survival thing that I've had my entire life.. and I'm very grateful to g-d for giving that to me.. Umm... the.. with the shit hitting the fan he and I became clo. r and closer and one - one story lead to another story and Bill got caught for cocaine... possession.. he was picking up a package of cocaine.. because we used to have a dealer in in San Diego.. who flied large quantities to us and hunner hunner hunner.. so-o he got caught.. the civilian authorities once they heard his story. and all of this was within two months of Michael's death, so he's in this big fucking wobble there, his career in the military they were investigating the pants off of him there, .hh the media's busy having a field day with a surgeon whose performing and the - the HATE campaign that went on ughhh.. spray painted graffiti on the side of our house, keying our cars. scraping a key down the side of the car.. d. ing Fa-a-g on the trunk.. you know stuff like that.. lovely stuff REA-EAL homophobic cuck.. the peace for the resistance.. a friend of mine named Charles was living in Los Angeles and he too had this thing, we pieced it together once we all, sort of started connecting... Charles was in throws of dying, he was very very sick - a-and I went to take care of him for a couple of days. while his mom just had to go back to Atlanta and take care of some business. so I went to look after him.. and all I did the whole time I was there was bitch bitch bitch bitch bitch bitch (whispering). (mimicking voice) "This fucking disease, this fuc".. here's a man whose like one step away from a lung machine.. ca-a-n't move. ca-a-n't do anything for himself and there I am winging like this and moaning.. and I can still remember his face.. he was completely gaunt and had that real AIDS look about him. and he said to me (mimicking voice) " OH-H-H.. for FUCK SAKE MARY.. SHUT UP, I AM SO TIRED OF YOUR FUCKING WINING w-what w-what I wouldn't give to be able to stand up right now and go take a piss.. and all you've done since you walked in the fucking door is whinge whinge whinge".. it was like.. ((clapping hands together)) thank you - reality- wake up - here's a man whose struggling-ing.. he's probably got da-a-ys left to live and as it turned out he had about a week.. he's got days left to live a-a-a-and here you are whining about your lot... and it was.. that - that was for me a turning point, I then went back to Los Vegas after looking after Charles and the date was the fourth of July, I remember it was independence day.. and I went to an area outside Los Vegas call-ll-ed Mount Charleston.. and it was a beautiful-l mountain retreat area in the middle of this desert.. absolutely beautiful.. went up there and sat on the mountain and I thought (mimicking voice) "I cannot be powerless here.. there's I-I don't know what this thing is.. I know it's not me-e-e.. it's not who I am.. how can I deal with this.. and this is the weird part. an- he one that always get the talk show hosts.. buzzing (laughing) =

I: = Umm (laughing)

D: In my mind I decided to give... HIV - a break.. for want of a better word.. I started looking what is HIV, hold on.. it's-s s-something in my body..it came into my body it must be alive. there's something living in it.. all right. what are my thoughts on living.. and I have a real issue of killing anything that lives.. I-I really have a real issue with that, with the exclusion of things like abortion.. I want go and kill a little bird.. all right, if, a women-n for some reason can't have a child she must have the right to decide what she wants... I recognised it's right to exist.. through a process, it's like.. what is .. I have a right to live here, I have a right to exist... actually - so does - the virus.. all right so if it's got a right to live.. I nee-ee-d to supp-port it in staying alive.. if it is this thing that moves between all of us.. the last thing it actually want's to do is to kill me off, because it's going to die in the process =

I: = o-o-okay..

D: = it didn't take too much.. .hh now as you can see in-n all this I've had a lot of practice in shooting up and slashing wrists and all that kind of cuck.. so this is the deal I struck.. I decided to give.. and this is an NLP process I discovered many years later, didn't know it at the time,

I: Ahhh

D: Umm.. I gave it a personality.. a shape.. a size.. a colour and I named it.. all right.. and it's going to be Joe. it's always been Joe.. all right and he - he and I gave it a male persona. oddly enough (xxx xxx xxx).. ummm.. and I literally transported it outside my body.. in-n ..not .. and it wasn't a visualisation, I had my eyes right open and I imagined this image in front of me.. and of of Mr HIV,. all right- Joe (pause) .hhh and I had this dialogue with.. which was the strangest experience, I said to him (mimicking voice).. " you know, I really acknowledge your right to exist, I acknowledge your right to live.. I acknowledge that you are powerful. I don't know what you are and what you want from me, but I can - I know that you're powerful, I've seen what you've done with Charles.. I've seen what you've did - done with Michael and at that time there was about three or four others.. distant people that had already started dying off.. the phone calls were coming in ..hh umm.. keeping in mind we're back in eighty three.. early part of eighty three and it was a frightening period... and I had, and I'd said to him (mimicking voice) "I acknowledge your right to exist.. I acknowledge your power.. I acknowledge that you can kill me.. I KNOW (clapped hands) this about you all right.. I don't know how but intrinsically,

uh instinctively I know it". and said (mimicking voice) "and I will do everything in my power to support your longevity and your well-being.. now I also need you to hear what I have got to say.. I have a right to exist, a right to survive, I have a right and I have the power to try and do whatever I can to try and destroy you, I am choosing not to do that, A truce state exists-s.. between us under the following conditions.. if you fuck with me I will throw every bullet that I have at you and I will destroy you and that includes taking my own life... =

I: = uh huh..

D: = if that's what I have to do, the other side of the coin is you never leave my body.. you never enter that of another human being, those are the two conditions under which we can negotiate our truce... .hh now I've ja-a-zzed it up,=

I: = yes..

D: = 'cause I've now got the lingo and the experience and hunner hunner hunner.. it was very basic. it was very stripped down and I was in tears.. I I'm fighting.. I'm not going to fight you for my life.. how can we co-exist.. and that's exactly what I did and every year on the fourth of July I repeat it.. last year I forgot.. I came down ((clapped hands together)) with double pneumonia four days later.. WAKE UP.. wake up.. so.. the dialogue thing-ng I have shared with other people.. and it was interesting we went to the-e.. I think it was the sixth international conference in Cape Town of People Living With Aids.. .hh I stood up and I shared my story with about. I think it was about a hundred, hundred and twenty people in the room.. shared my longevity story with them. as a sort of like a rare hope kind of speech. 'cause in those.. then it was still a very bleak period.. it was just before the prolease inhibitors had been introduced..

I: uh huh

D: Umm.. and I told my story.. I told them the story of Joe and the fourth of July experience and the rest of it.. and there were people crying in the audience because they had done something very similar.. different reasons and different motivations be it, one was a Buddhist and had this non-aggression a-a bel.. belief.. another didn't believe in taking life.. another one did it because it was the only thing he knew how to do, and made it a religious experience for themselves, .hh but everybody did it for their own reason, and there is an interesting book you need to read by John Kaiser.. all right I'll give you the name remind me,

I: I have it..

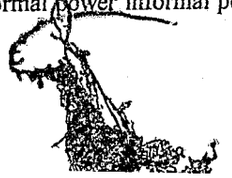
D: have you got it..okay.. the letter writing process that he puts people through.. essentially the same type of thing.. e-stablishing-ing.. a joint power base versus power over power under.. all right.. don't under power me.. don't over power me kind of scenario.. I trie-ie-d to transfer that over to Bill.. Bill came from a-a background of - of complete poverty. I mean a a really really poor background.. based in Miami.. Ohio.. and his.. because he became a doctor there was a tremendous attachment to the material world and what that represented, because that's kind of where he was.. and yet he was a very spiritual devout Roman Catholic ... lots of (xxx xxx xxx) beating himself up for .h starving children on the other side of the world.. so-o he had a very big heart.. so it's interesting the conflict in him because he he.. I think towards the end of his life he was able to reconcile all of this stuff and it made sense to him.. I was always like the cheerleader in the background, you know the wind beneath my wings ?

I: Oh yes..

D: That sort of became our song.. I was the loud outspoken one .hh and he fell very much to the background and yet in the background he was hugely powerful. because he was the one who ran all the ideas and stuff I came up with. and that we created, so it was a very powerful combination.. .hh the military, the the going back to the cocaine bust and it's a significant part of why this is important.. the cocaine bust uh.. Bill was let off by the civilian authorities.. they dropped it.. in the mean time I had started work in a travel agency and I had befriended a women named Janine.. I didn't know Janine's story.. in those days anybody who would talk to me was like my friend, an instant confident. and a lot of it I I used, I used a lot of informal power in disclosing stuff I should never have disclosed to her thinking she was my confident.. well she wasn't

I: When you say informal power ?

D: Formal power is the manager the person who is supposed to have power.. all right.. dad has the power in the house because he is the father figure..the boss has the power because he's that.. the pecking order.. informal power is the secretary.. the one who can actually block me from getting through because she's got a hard on for me about something and.. the communication breakdown, so there's formal power informal power a wife has informal power in the traditional marriage situation.. because



she can talk in the business sense.. (mimicking voice) "you know he's a very talented man.. but you know I wish I could get him to do blah blah blah"

I: Okay.. I hear you

D: I used my informal power completely oblivious to this.. and I shared with her first of all about HIV infection.. still calling it GRIDS in those days .. told her what was going on.. didn't .. and she was hugely supp-pportive and (mimicking voice) "and my sons a drag queen hunner hunner hunner..you've got a friend in me", little did I realise at night she used to hit the sauce..

I: Um

D: When she hit the sauce... (swallowing) she became very vindictive.. she had a thing.. because Bill was a surgeon. they never pulled him off of surgery he was still functioning as a surgeon but they started this whole secret investigation on him.. .hh still doing surgery stuff and umm.. I then shared with her about his cocaine bust.. at the airport.. When she called and told them that he was a homosexual and a homosexual relationship with this GRIDS thing.. they said (mimicking voice) "we know we are already doing an investigation.. so we can't.. you know there is nothing more that you can actually tell us .h other than when we need to court martial him we'll bring you in as a witness..she was perfectly okay about this, all of a sudden.. all of this unbeknown to me =

I: = Oh my-y

D: (cough) This women would come to my home, pick me up every day and take me to work bring me home drop me off.. blah blah blah umm.. when Bill got released from the DA's office and they said (mimicking voice) "okay under the circumstances. it was a bad judgement call blah blah blah blah blah".. slate clean.. I went and told her (mimicking voice) "Oh my g-d fabulous new Bill's got off" (whispering).. that night she calls-s the police [

I: [Oh my g-d..

D: on the base.. and the military police don't follow the same law as regular police.. they can do <u>whatever</u> they want.. because he's military.. he's owned by the government.. so-o-o they.. they bring him.. in arrest him.. throw him in the stockade go through that whole song and dance with him (pause). during all of this stuff and and please understand this is all like within a four month period this whole thing happened.. so it was just his whole world fell apart.. my-y <u>entire</u> world - fell apart.. I went from be-e-ing at the age of twenty one I had four hundred thousand dollars to my na-a-me.. to twenty three-ee.. scraping to try to make things work.. okay I pissed away a lot of money .hh and the and then trying to find a cure.. that's another whole story, you know travelling all over the world trying to find the elusive cure for HIV AIDS (laughing).. oh fuck.. the money I've spent it's frightening.. umm I'm getting derailed again where was I ?

I: Bill was thrown in Jail.

D: They started a court martial proceedings against him.. we hired.. they - they filed a number of charges against him number one homosexuality, number two using a pho-o-ne to secure drugs.. a national phone-line thing.. uh, using the United States postal service.. and homosexuality.. they nailed him for four charges.. did I say homosexuality ? uh I think I did.. umm they couldn't prove the homosexuality charge but that cost us about twenty thousand to get that <u>dumped</u>.. they couldn't.. the - the phone thing I took the wrap for that I said that I ordered my arrangement to be shipped so they couldn't press charges against me because the civilian suite had already been dropped =

I: = yes..

D: the military had no jurisdiction over me.. .hh they then bugged our house.. while we were away on a trip in Northern California or actually Southern California down in La Jolla.. we were down there for a weekend.. they came and they bugged the house.. they knew <u>every-y-y-thing</u> we did.. they knew everything we said and every defence mechanism we had... this took place over a period now of <u>eighteen months</u>.. with this <u>pressure</u>.. Bill was not allowed to practice.. they now removed him, not because of the HIV. but because of cocaine.. he would do facial reconstruction and they would use pure cocaine for numbing.. process.. he was an oral surgeon so he would do all the reconstructive stuff.. umm.. so they withdrew him from that and made him go and check parking meters and public (xxx) machines to make sure they were stocked. he's a man with four degrees.. four degrees (laughing).. OH it was it was HIDEOUS it was ABSOLUTELY <u>hideous</u>.. walking in supermarkets and people would literally avoid us,. going out onto the car and finding someone had taken some snot and spat all over the front of the car =

I: = Aahh

D: = cause they recognised our cars.. In the mean time Bill is getting sicker.. he is now starting to manifest symptoms they they're showing that there is liver enzyme imbalance.. they're showing myosytis in the legs.. there's still no name for this disease it's still called GRIDS.. umm it wasn't until-l-l... May-y-y of-f eighty four they really said that okay this was a thing called AIDS.. cause it went from GRIDS to-o-o what was it ?.. oh g-d there's another name for it.. first you were a carrier..anyway.. where was I ?

I: In terms of Bill you said he was getting sicker and sicker.

D: His defence.. the governor required him to go against a psychiatric board.. they wanted to prove his homosexuality. they wanted to prove his drug addiction. they wanted to prove his perverted lifestyle.. supposed perverted lifestyle, he was such a good man, ummm, so they sent him onto a - to a psychiatric evaluation thing where he had to go to these lunatic bins a-and go through the whole process of.. here's a man whose already his resources are so low, he's got so little left, now they figure to take away his career.. if he gets court marshalled he's facing twelve years in Levinworth. .hh he faces um loss of his income, no medical benefits at all and now a-and because he he demoted for seventeen years there was no way in hell he was going to get an insurance policy, no one would insure.. all these pressure is coming at us... I in the meantime start noticing that I'm feeling a bit better [

I: [better

D: .. the strange things are going away like the the shingles for example... okay that's gone, I don't have to worry about that anymore.. thrush didn't k-kick in till about two years after that.. but the main tell tell signs are going.. however-r I was also - now cranking cocaine.. I was I was really partying a lot on cocaine.. and it became it became the drug of choice it became the drug of necessity.. I was taking pills to wake up in the morning.. I was doing.. I was taking pills to go to sleep at night.. I was doing a line to wake up.. and it was that kind of treadmill process.. we decided that we were going to buy a hotel in the Cayman Islands and that's where we were going to settle. that was the big picture.. the [illegible]on got smaller and smaller and smaller, the more our resources went into the fight for-r health.. fo. Bill. because the medical they wouldn't treat him for anything, I mean they would give him blood transfusions and that was about it.. the-e-e court martial was becoming hugely expensive because we had to get a t-team of top lawyers to represent and and to get a psychiatrist privately and have all the sessions, it was just this big megila we had to go through, .hh plus huge amounts of cocaine. and now we were starting to form networks with other HIV positive people.. there were only a handful. three or four people but it was nice to know that they were there. and one or two of the old friends came back and said (mimicking voice) "I'm really sorry. you know can we make amends", and that was really cool.. some, a lot of them vanished by the way side, ummm.. when Bill eventually was retired from the military, during the court martial the judge said (mimicking voice) "beyond any reasonable doubt you had, no resources an-nd the truth is I'm surprised you hadn't done more cocaine, and you weren't using heroine you weren't doing everything else", the judge was a very compassionate man ..hh umm and released Bill-ll.. from all charges that were dropped.. but the emotionall-ll, uh.. that is what basically started Bill dying.. we (xxx) about this place in the Caymans.. well it got to a point where we couldn't afford to do any of that an-n-d I had to get a job Bill had to get a job an-n-d.. he had a pension he had a a decent pension from the government.. but it wasn't enough to sustain the lifestyle with cocaine and the.. dinner parties that we now wanted to have and get a new life going.. we jettison from-m Las Vegas and we move to Gai-ai-nsville Florida.. Ohh-h (laughing) g-d what a mistake.. Bill was offered a position as a teaching-ing lecturer surgeon person.. at the..there was a teaching hospital there.. Bill goes in for the final process and he's now meeting the dean of admissions and hunner hunner hunner.. and the Dean of admissions.. Bill happens to drop.. a name of his former lieutenant.. uh. of his former commander.. this guy happens to make a note of it. because he happened to go to medical school. with him[

I: [Oy oy..

D: ..he ca-ll-ls and of course when we arrived in Gainsville the slate was clean.. nobody knew anything about us.. we were these two new moffies in tow-ow-n and it was going to be a lekker jol and we connected with the gay bar and got into the community, and this was the first five or six months it was really.. quite an amazing period.. we were back in our power.. 'cause nobody knew us.. but there was always this little.. monkey in the fucking corner chirping away.. ((angrily stated)).. umm, so-o-o.. the doc.. he calls this doctor friend of his who he went to school with an-n-d of during the course of the conversation the guy says (mimicking voice) (laughing) "Of course we're not thinking of you know having him.. he's got this thing called AIDS" [

I: [Oh n[

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