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Beneath the wings of Aidos (Goddess of Shame): Women finding the courage to live with HIV and the strength to die of AIDS

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A Zen master says:

O Young folk
if you fear death,
die now!
Having died once,
you won't die again

- Hakuin

ABSTRACT

This study describes the subjective psychological experience of African women positively living with and dying of HIV/AIDS, with a focus on the significant cognitive, emotional and social themes involved in their subjective sense of coping. HIV-positive African women have been identified as being at risk psychologically, due to gender inequality in African culture and society and the stigma that surrounds HIV/AIDS. Their traditional role as caregivers also places them at risk, but highlights the importance of understanding their experience in order to assist these women and their children. Drawing on interpretive methods within a qualitative research approach, ten women who are coping with their HIV-positive status were interviewed in order to gain an understanding of their experiences of coping with HIV/AIDS. The analysis of the interview material suggests that coping is a process of disconnection and reconnection that entails the ability to know one's own experience. Coping was found to be a process of mourning in which the individual moves from a time of not coping toward acceptance of their status and the changes this necessitates in their relationships. Resolution of mourning seemed to entail greater integration of these women's sense of themselves and psychological strength was found to originate in coping with adversity. The study draws on three theoretical approaches, namely positive psychology, object relations theory and analytical psychology. Carl Jung's theory of individuation and Joseph Campbell's interpretation of it, The Hero's Journey, was used as a frame for the theoretical discussion. Within this frame, Elizabeth Kubler-Ross' stages of mourning were integrated with Donald Winnicott's description of separation in the move from dependence to independence, Winnicott's ideas around the capacity to be alone, Melanie Klein's description of the move from the paranoid-schizoid to the depressive position and Wilfred Bion's ideas around the desire to know one's own experience. Throughout the discussion a number of concepts from positive psychology were explored, such as: coping styles, social support, participation in life, positive goals, autonomy and resilience. The core of Jung's theory, which is the integration of all aspects of the self, allowed space to explore distress and coping, both of which are entailed in the process of coping.

Key terms: coping, resilience, HIV/AIDS, women, self, identity, individuation, autonomy, mourning, social support, dependence-independence, integration

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DECLARATION

I declare that this research report is my own, unaided work. It is being submitted for the degree of Doctor of Philosophy (Psychology) at the University of Pretoria. It has not been submitted before for any degree or examination at any other university.

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Katherine Bain

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Date

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CHAPTER ONE

INTRODUCTION

For seasons and seasons and seasons all our movement has been going against our self,

a journey into our killer's desire

Ayi Kwei Armah

1.1. INTRODUCTION

HIV/AIDS is a social reality in South Africa of such a magnitude that it has become a human rights issue. According to our Constitution and 'Batho Pele', the spirited cry in our National Health Department, all people are afforded the right to quality healthcare that embraces the human rights of equality and dignity (Department of Public Services and Administration, 2005). However, the current strain the health system in this country is under does not bode well for the future care of HIV infected people, considering the current and projected estimates of prevalence rates in our population. Current statistics and the relevance of mental health with regards to HIV/AIDS are discussed in detail later in this proposal. Manganyi (1981) wrote:

> Mental health practitioners will know from their own experience that the mental health problems of this country outstrip by far the planning and institutional provisions for prevention and treatment that exist today. We do not need statistics to know that the provision of services for blacks, other than state institutions for psychotic patients, remain dismally inadequate both in terms of mental health professionals as well as organizational structures for dealing with problems other than those that require hospitalization. For various reasons, the services of mental health societies for blacks will remain helpful but hopelessly inadequate…we need to develop a plan, a strategy for dealing with the realities of African existence in South Africa…we need to face the fact that large numbers of our people are ordinary, working folk with limited education in most instances…we may not depend entirely on prevailing practice elsewhere without taking our own circumstances into serious consideration (p. 101-102).

Manganyi wrote these words in 1981. Since the political changes of 1994 and the institution of community service for clinical psychologists in 2002, the situation has

improved somewhat, with greater access to mental health services being provided for rural communities. However, the numbers of people being infected and affected by HIV/AIDS has greatly increased the demand for mental health services and hence, we are again in a situation where the provision of these services for those most in need are "helpful but hopelessly inadequate". In terms of the researcher's own experience thus far in the field of psychology and psychotherapy, HIV/AIDS related problems are fast becoming a large proportion of the work in the public health sector. For psychologists, dealing with the psychological consequences of illness and imminent death of people infected as well as those affected i.e. family, friends and caregivers by HIV/AIDS is becoming a daily task.

Dealing with HIV/AIDS and the psychological ramifications for those infected and affected means assisting people to face sickness, loss and death, while still maintaining emotional investment into the attachments and activities that life entails. While the more traditional psychodynamic theories have a pathology focus and deal with the implications of loss, positive psychology focuses on coping and positive outcomes. HIV/AIDS entails both. It is felt by the author that perhaps what is lacking is an exploration of what these theories might possibly offer when integrated.

Despite impressive advances in medicine, a criticism that is often levelled against Western medicine is that as advances have been made, death has become increasingly hard to deal with. This has had implications for society at large, where death has become an issue that is skirted (Kubler-Ross, 1970). In the last century, Western medicine has moved death as far away from the realm of life as possible. Fewer people died at home surrounded by family; they died rather in Intensive Care Units hidden in hospitals. As a society we have come to value youth and beauty, and the wisdom of the old, sick and dying is being lost as we attempt to deny the reality of mortality.

However, HIV/AIDS in South Africa, with its pandemic proportions, is challenging this status quo. The scientific Western approach to illness and death seems to be at odds with the realities in government hospitals, where due to bed shortages, people are once again

being sent home to die. As the reality of numbers sinks in, there is a movement toward community care, with family members being taught to dress sores, give medication and care for their loved ones at home. The HIV/AIDS epidemic in this country is not going to happen behind the frosted glass doors of an ICU: South Africans are being confronted more and more with the ugliness of sickness and the deep sadness and helplessness that death evokes.

While the roll-out of anti-retroviral treatment in South Africa has lengthened the life expectancy and improved the quality of life of many HIV-positive people, there is no escaping the fact that being diagnosed HIV-positive entails a psychological reorganization or 'getting to grips with' one's own mortality. This seems to highlight the need for a more contextually aware approach to theory that enables psychologists to assist people to live productively while preparing for death. An important aspect of the South African context is culture. Although black African culture does seem to embrace the spirit of community more, traditional beliefs around the causes of HIV as being related to having angered ancestors and/or witchcraft have contributed to the stigma surrounding this disease (Kalichman & Simbayi, 2004). However, as discussed above, it is likely that Western conceptions of and attitudes towards illness have also contributed to this.

The researcher feels that we as psychologists are not well enough equipped to deal effectively with the types or magnitude of suffering this epidemic is going to continue to produce. The majority of people with HIV in South Africa cannot afford private health care, let alone private psychological services and due to non-market related salaries and constant hospital budget cuts, the state health services do not employ sufficient psychologists. Hence, there are not enough resources to offer even short-term individual therapy, let alone medium to long-term individual psychotherapy to all patients requiring intervention. As psychologists we are seeing the impact that illness and the loss of a spouse is having on HIV positive parents who are raising children and the economic and psychological implications this has for the surviving parent and the children's mental health. We are seeing children from child-headed homes, and although we can project

the possibilities, we do not yet know the full implications of this on the mental health of these children. We are seeing more and more children who are being placed in foster/children's homes and witnessing the mental health impact of this, helpless to provide the extent of services that these children require. We are seeing more grandparents who are caring for grandchildren and seeing the strain this places on them both financially and emotionally. We are also seeing more and more HIV positive children who, due to the provision of antiretrovirals are surviving into adolescence. This new patient community has a unique set of mental health needs, the extent of which we are only now discovering. The establishment of a healthy and productive identity is difficult enough in adolescence without having to also contend with the fear and stigma that being HIV positive can elicit.

Overall, the numbers of HIV/AIDS infected and affected people requiring mental health services is steadily growing and our current approach is not meeting the mental health care needs of these people. Psychology, as a largely Western discipline, has a lot to learn in terms of coping with and assisting others to cope with this illness. It has been suggested that perhaps the African community sentiment needs to be heard and that group and community intervention would perhaps be better than individual psychotherapy. Western psychological treatments, which are based on individualistic notions of mental health, tend to focus on individual coping styles and while these therapies can be effective when the therapist is culturally sensitive, there are suggestions that perhaps the focus should be on encouraging more involvement of extended family and the community. In other words, we seem to be uncertain of the most effective way to intervene to assist these people.

For these reasons and the fact that current statistics are showing that women are the group with the highest infection rate, especially African women (Shisana & Simbayi, 2002), this study aims to identify and describe the themes involved in African women's experiences of coping and living positively with HIV and dying of AIDS, in order to gain an understanding of psychological strength and resilience in the face of this unique form of suffering and anticipated death.

Studies already done on the coping styles of HIV-infected individuals have found differences in coping styles that correlated to age, gender, ethnicity, sexual orientation, socio-economic status and level of education (Tarakeshwar, Hansen, Kochman & Sikkema, 2005). Hence, although largely generalized, the assumption can be made that the experiences of HIV-positive white women originating from Western cultures is likely to be different to those of the HIV-positive African women, as would the experience be different for women accessing treatment in the private sector from those accessing treatment from a government hospital. Therefore, in order to avoid too wide a research scope and in order to gain a non-Western perspective, the study focuses on the experiences of African women.

Indirectly, the study hopes to integrate the more well-used traditional schools of psychological thought with a more 'positive' psychological paradigm, taking into account cultural influences, in order to create a more accessible and effective approach to understanding and dealing with the psychological aspects of HIV/AIDS for women in psychotherapy.

1.2. RESEARCH AIMS AND OBJECTIVES

This research will describe the subjective psychological experience of women positively living with and dying of HIV/AIDS with the aim of identifying the significant cognitive, emotional and social themes involved in their subjective sense of coping, from a qualitative theoretical approach that aims to integrate positive psychology, object relations and analytical understandings. The objectives of the research are to: discover a more culturally appropriate understanding of these women's experience; integrate current theories in a new understanding that focuses more on the mental health promotion of women; and provide further treatment options with which psychologists can work in order to provide an effective service to HIV-positive women patients.

1.3. USE OF TERMINOLOGY IN THE STUDY

In order to clarify the concepts to be considered in this study, it is important to define various terms. While HIV (Human Immunovirus) refers to the actual virus that is transmitted and which infects the body's immune system, AIDS (Acquired Immune Deficiency Syndrome) refers to the effects of the HI virus on the body and which is usually only diagnosed in Stage 4 of the illness. The generally accepted staging for HIV infection is that of the World Health Organisation. While Stage 1 includes seroconversion illness and persistent lymphadenopathy, the performance status (1) is fully active and asymptomatic. Stage 2 includes less than 10% weight loss, herpes zoster, recurrent upper respiratory tract infections and minor mucocutaneous manifestations. The performance status (2) is symptomatic but fully active. Stage 3 includes more than 10% weight loss, chronic diarrhoea, prolonged fever, oral candida, chronic vaginal candidiasis, severe bacterial infections and pulmonary tuberculosis. The performance status (3) specifies being in bed less than 50% of the preceding month. The final stage is Stage 4, which includes extrapulmonary tuberculosis, recurrent pneumonia, pulmonary candidiasis, cryptococcal meningitis, progressive multifocal leukaencephalopathy, invasive cervical carcinoma, symptomatic sexually transmitted infections not responding to treatment and a variety of other illnesses and infections. The performance status (4) specifies being confined to bed for more than 50% of the preceding month (World Health Organisation Clinical Staging System).

Definitions of coping include "to contend or deal, esp. with success; to be able to handle" (Halsey, 1979, p. 222). According to the 'Brief COPE', which is a measure of coping styles, coping is a wide term made up of a number of other concepts: active coping, planning, positive reframing, acceptance, humour, turning to religion, venting of emotions, mental disengagement, denial, substance use, behavioural disengagement, and emotional support (Carver, 1997). Coping is also affected by negative life events, such as: serious illness in other family members, loss of home through disasters such as flood or fire, eviction from home due to inability to pay rent, loss of job, legal problems,

divorce or separation, pregnancy/ miscarriage/ abortions/ stillbirth etc. The number of and perceived subjective impact of these events have been shown to influence a person's experience of coping (Carver, 1997). Positive life events have also been shown to have an impact on coping, as can be seen by the inclusion of positive events, such as a vacation, an outstanding personal achievement, getting married and a change in recreational activities, in the Holmes-Rahe Life Events Rating Scale. This scale is based upon the theory that one of the most significant sources of stress, which is strongly related to coping, is change (Holmes & Rahe, 1967).

Three primary types of coping strategies have been identified: efforts to change the situation, which includes problem solving and implies a more active, problem-focused approach; efforts to alter cognition about the situation, which includes reframing and reappraisal of a situation; and efforts to alter the unpleasant emotional consequences of a stressful situation, which can include the use of drugs, alcohol, music or distraction techniques (Moos & Billings, 1982). Most of these coping strategies are conscious, or if attention was called to them, they could be called to consciousness, however, in terms of psychodynamic theories, coping refers, in most cases, to defence mechanisms, which are largely unconscious processes. Defence mechanisms are described as "unconscious mental processes aimed at protecting the person from experiencing unpleasant emotions (particularly anxiety) or bolstering positive affect" (Westen, 1996, p. 438). It must also be taken into account that variabilities in terms of coping strategies used will occur over the course of the HIV infection and AIDS stage and from person to person. Thus, it is more useful to view coping as a process rather than as a fixed style.

Thus, provisionally, the term coping will be considered to mean the process of dealing with an HIV-positive diagnosis and its consequences, consciously or unconsciously, with success (success in this context meaning without profound prolonged negative impact on social, emotional or occupational functioning). It must be noted that this definition is open to change during the course of the study. The fact that the study aims to explore the participants' experience of coping suggests that their concepts of and opinions about what coping means is the area of focus. The findings of the study are expected to modify this

provisional definition and provide a more specific and context-appropriate definition of coping as relating to these particular HIV positive women. Coping as a concept encompasses a number of other related terms, such as strength and resilience. General definitions of strength include:

> a state or quality of being strong; power to sustain or resist attack, force, strain or stress without breaking or yielding; power or ability to act, command, enforce obedience, or make decisions; firmness of mind, character, will or purpose; moral courage; legal, moral or intellectual power, influence, or effectiveness; vigour or vehemence, as of feeling or conviction; degree of intensity…degree of concentration or effectiveness;…one who or that which strengthens; source of power or force (Halsey, 1979, p.987).

A general definition of resilience, according to Halsey (1979) is the quality of being capable of recovering quickly or easily, from, for example, depression or adversity. According to Strumpfer (2003):

> Resilience derives from the verb resile, which means that when a thing is compressed, stretched or bent, it tends to spring back elastically, to recoil and resume its former size and shape. In the case of humans, it, firstly, refers to recuperation but it could also include constructive and growth enhancing consequences of challenges or adversity(p. 70).

While resilience described in these terms seems to refer to living through an experience and recovering from its negative sequelae, Carver (in Strűmpfer, 2003) refers to the concept of 'thriving', which is a situation in which an individual does not merely return to a previous level of functioning, but surpasses it. In the case of HIV/AIDS, this would refer to a person experiencing a sense of being mentally more healthy or psychologically stronger.

In order to define living positively, it is necessary to define each concept in isolation and then integrate their meanings. To live, according to Halsey (1979) is to "be alive; have life; to continue to exist; remain alive; to support oneself;…to get the fullest enjoyment from life [as in] *after his 21st birthday he really began to* live" (p. 598). While in medical terms 'positive' is defined as "indicating the presence of a particular disease, germ or other abnormality" (Halsey, 1979, p.783), 'positively' implies a variety of other meanings such as: a state of no question or doubt; something that is clearly expressed, definite, or emphatic; a quality of expressing, containing or implying affirmation or acceptance; a tending or moving in a direction considered to be one of increase, improvement, progress or forward motion; as well as the possessing of or being characterised by the presence of real or particular qualities (Halsey, 1979). Thus, to 'live positively' could be seen to have a plethora of meanings. In terms of the medical definition, 'living positively' could even be seen to be a play on words as it could be taken to mean 'to continue to exist or remain alive with the presence of a disease'. However, this covers all people infected with HIV and does not capture the essence of progress or affirmation in terms of attitude toward living with HIV that this study intends to capture. Thus, for the purposes of this study 'living positively' refers to a clearly expressed feeling or attitude of acceptance toward supporting oneself and continuing to exist in the presence of HIV in a way that implies forward movement or progress.

Dying can be considered to mean: "approaching death; about to die;…drawing to a close; fading" (Halsey, 1979, p.318). However, it should be kept in mind that dying and the meanings attributed to it hold a number of social and cultural meanings, specific to a person's cultural, religious and social backgrounds and beliefs.

The HIV/AIDS epidemic in South Africa is surrounded by a pervasive stigma that permeates some segments of the society (Kalichman & Simbayi, 2004), thus it will most likely feature in this study. Stigmatization can be defined as a form of discrimination or 'othering' that has its roots in both individual fear and social control (Campbell, Foulis, Maimane & Sibiya, 2005). This concept will be explored further in the literature study. It is important to note that stigma implies a sense of shame.

Due to the fact that this study focuses on women's psychological experiences of HIV/AIDS, the last term that needs definition is that of gender. While the term sex refers to a biological distinction between male and female, gender is regarded as referring to the psychological or social meaning of being male or female (Westen, 1996). This social meaning will take into account the implications of gender from within the context from which the participants speak.

1.4. MOTIVATION FOR THE STUDY

It is estimated that by the year 2010 there will have been 5 to 7 million cumulative AIDS deaths in South Africa and that by the year 2015, 5,7 million children will have lost one or both parents (Dorrington, Bourne, Bradshaw, Laubscher & Timaeus, 2001; Johnson & Dorrington, 2001). It is estimated that 7 million South Africans are currently infected with the highest prevalence rates among young people, especially teenage girls (Coombe in Hartnell, 2005). Currently there are more than 800 000 children under the age of 18 who have lost their mother to AIDS (Children's Institute of the University of Cape Town, 2002). There are more than 1600 new HIV infections per day (Shisana & Simbayi, 2002; WHO/UNAIDS, in Kalichman & Simbayi, 2004) and prevalence rates of up to 33,5% have been found amongst women by the antenatal surveillance survey conducted by the Department of Health (Freeman, 2004), which is considered the most systematic, ongoing measure of HIV prevalence. According to the Department of Education the prevalence of HIV/AIDS among pregnant women under the age of 20 years has risen 65,4% from 1997 to 1998 (Hartnell, 2005).

In 2003, the world spent $4,7 billion to combat HIV/AIDS in poor countries. In his 2003 State of the Union Address, George W. Bush pledged $15 billion over a 5-year initiative to combat the disease. However, these sums, as large as they are, would have been enough to staunch the AIDS epidemic in 1996, not in 2005. To make a difference, it is estimated that $12 billion is needed in 2005 alone (Rosenberg, 2005).

In light of these statistics, it appears that South Africa is faced with a disease that has immense social and financial implications. In the face of a full-scale epidemic, while the South African Government practices 'damage control' and prioritizes the prevention of further infection, it is the Departments of Health and Social Services that now bear the brunt of the approximately 7 million people already infected (Dorrington et al., 2001). The provision of two combinations of anti-retroviral drugs is, however, yet another double-edged sword in the battle against HIV/AIDS, as the risk of the emergence of resistant strains of the virus exists. While it is impossible to predict the situation years from now, the current reality is that approximately 7 million people in South Africa are living with this disease – suffering from the knowledge or suspicion of infection and knowingly or unknowingly spreading it further. "That there will be significant mental health consequences arising from the pandemic is hardly debatable. With the above-mentioned numbers of people dying, orphaned, and caring for the ill and dying, negative psychological sequelae are inevitable" (Freeman, 2004, p. 152). Despite the immediate sequelae of distress and grief evoked by a terminal diagnosis for the HIV-positive woman and her immediate family, there are also the physical implications with regards to the course of the illness and the financial implications this has in terms of lost income for the family.

The importance of parental influence during childhood on developing personalities is core to many psychological theories of personality. The immense stress that will be faced by the 3 million children it is estimated that will be orphaned by 2015, could contribute to a mental health disaster that could in turn create social chaos. According to Freeman (2004):

> A number of these children or young adults will suffer from depression. It has been previously noted that people with depression are more likely to indulge in risky behaviour, including risky sexual behaviour, substance abuse and violence. Given poor bonding, lack of structure, and inadequate love and caring, it can be anticipated too that a large number of children

orphaned by AIDS may become susceptible to personality disorders. Anti-social personality disorder is likely to feature prominently. It is impossible to predict how many of these orphaned individuals will turn to crimes such as rape and murder, but the circumstances would be conducive to a large number of such eventualities. People turning to less serious crimes due to poverty, need, and perhaps lack of respect and caring for others seems inevitable (p. 152-153).

These speculations in themselves are justification enough for more research into ways of assisting HIV-positive mothers to fulfill their roles effectively despite HIV. The slogan of many of the Prevention of Mother to Child Transmission (PMTCT) campaigns, is 'Save the mother, save the baby'. Perhaps this may also ring true for mental health interventions.

Ultimately, while education to promote prevention appears to be the hope of victory in this battle, the already physically and psychologically wounded cannot be ignored. To assist people to cope with their diagnosis and thereby maintain their health for as long as possible, in order to continue being emotionally and economically productive members of families and society, needs to be a part of the country's management plan. It could help lessen the impact of HIV/AIDS on our society and break a cycle of ignorance and suffering that promotes the spread of the disease.

The mental health services provided to HIV infected individuals in South Africa have tended to originate from the medical model and have thus not been found to be empowering to users (Freeman & de Beer, 1992). Hence, this study aims to explore understandings of HIV/AIDS related mental health in a way that is more empowering and culturally appropriate. In South Africa, mental health professionals already experience themselves as overburdened and tend to resist additional responsibilities and functions (Freeman & Pillay, 1997). According to Freeman (2004) our overburdened health care system has important implications for how AIDS-related mental health will be dealt with. While in developed countries there is a referral chain to higher levels of skill, the

situation is very different in developing countries. This then affects who does what and how.   Freeman (2004) explains that even where community-type interventions are suggested, the relevance of these to developing countries is questionable due to the lack of community resources, which make possible replication unlikely.

For example, in the first world, HIV/AIDS is still regarded as primarily a homosexual disease and thus a significant proportion of the literature focuses on homosexual men, while in South Africa, there are in fact more heterosexuals and indeed more women than men infected with HIV (Shisana & Simbayi, 2002). This study also hopes to further the understanding of the particular needs of women within the context of a developing country, in the hopes that this understanding can contribute to better mental healthcare interventions.

According to Freeman (2004):

> The HIV/AIDS pandemic will have massive implications for mental health in sub-Saharan Africa. While research in developed countries is quite advanced in this area, and while some of this research is relevant and important in developing countries, understanding and dealing with a disease of relatively low prevalence and which is mostly under control is vastly different from the considerations required of a growing epidemic which seems likely to kill a significant proportion of the population. The mental health implications of HIV/AIDS will be felt by individuals, families, communities and society as a whole…Given the magnitude and pervasiveness of HIV, it is argued that the mental health 'whole' will be far greater than the sum of the parts. This means that much more research and interventions will have to be put into place in order to obviate a potential mental health and social 'disaster' (p.139).

Hence this study is significantly relevant to the future of our country. The reality is that while prevention programmes are being found to be having an impact on rates of infection (Simbayi, Chauveau & Shisana, 2004), they are too late for many. There are already an overwhelming number of people already infected and the majority of them are women. And although the rates of infection are slowing, they have not stopped. These women are also mothers, playing an integral role in influencing the psychological health of tomorrow's adults. Another reality that studies have shown is that the majority of these infected women are likely to need mental health intervention – a job to be done by too few who know too little about how to intervene in an effective and culturally appropriate manner.

In addition, years of research into the influence of negative factors such as "stressful life events, depression, and hostility on disease progression and quality of life after the diagnosis of devastating illness, behavioural medicine is now turning its attention to the possible protective effects of positive psychological factors such as meaning, control, and optimism" (Ironson, Balbin, Stuetzle, Fletcher, O'Cleirigh, Laurenceau, Schneiderman & Solomon, 2005, p. 86). Ironson et al. (2005) conducted a study into whether optimism protects against disease progression and found that "optimism predicted slower disease progression (less decrease in CD4 and less increase in viral load)…those low on optimism (25th percentile) lost CD4 cells at a rate 1.55 times faster than those high on optimism (75th percentile). Optimists had higher proactive behaviour, less avoidant coping, and less depression" (p. 86). This study highlights the need to look at what allows certain people to cope better than others and to try to understand how these factors are developed. The fact that the study will be done using qualitative methods in order to best capture the lived experience of these women is supported by the following statement:

> Understanding the lived experience of people with HIV is crucial for the planning and implementation of appropriate health and social care. However, academic studies that explore the actual experiences of people living with HIV/AIDS are few and far

between (Green & Sobo in Anderson & Doyal, 2004; Lewis, in Anderson & Doyal, 2004, p.95).

1.5. RESEARCH DESIGN

This brief discussion of the research design serves as a preview and a more detailed discussion is presented in Chapter Four. A qualitative research design was chosen for the study due to the fact that the aim of the study was to explore and describe the subjective experience of black women living positively with and dying of HIV/AIDS and qualitative research methods are particularly relevant for studying the lived realities of people within their contexts. Qualitative research approaches allow the information gained from the study to guide the research process and thus presents a description of the lived experience of these women.

The participants in this study consisted of ten HIV positive black women who were identified as coping well with their HIV status and who considered themselves to be coping. The participants were sourced from Coronation Hospital, a women and children's hospital in Johannesburg. The number of participants was determined by the number of interviews that it took to reach satisfactory saturation of the data. In order not to enforce the author's idea of what the concept coping means, it was decided that the definition of coping would be allowed to emerge from the study itself, through the integration of the opinions of the participants themselves and the opinions of the health professionals who referred the women for the study.

The data collection technique used was that of semi-structured interviews, consisting of open-ended questions to gain the participants' subjective experience of coping with their status, their illness and its implications for their lives. Qualitative research interviews attempt to tap into the 'experiential world' of the participants and to gain an understanding of their 'meanings'. This method suited the exploratory aim of the study. Certain questions were asked of all participants along various broad themes relevant to

the topic, but some ad hoc questioning at the interviewer's discretion was used to explore various answers or 'meanings' more fully. With permission from the participants, the interviews were taped and transcribed by the author. A thematic analysis was then done to identify significant themes in the participants' experience of coping, living positively with and dying of HIV/AIDS.

Although a preliminary literature study was done, the results that were gained were allowed to inform the important themes for the literature study. Although the idea of combining object relations theory and positive psychology, using psychoanalytic theory was decided upon before the outset of the data collection, the themes that emerged from the interviews were used to inform the focus of the theoretical discussion on these theories and even to inform the use of certain theorists within the approaches.

Lastly, the information gathered by the study was taken back to the participants and shared with the staff involved in the treatment of HIV positive women at Coronation Hospital.

1.6. THEORETICAL FRAMEWORK

In addition to exploring African womens' experience of living positively with HIV and dying of AIDS, one of the aims of this research was to integrate traditional psychodynamic and newer positive psychology approaches using the data from the study in order to provide a unique in-depth understanding of these women's experience. Hence, three theoretical approaches are used in this study, namely, positive psychology; object relations theory; and analytical psychology.

The theory of Carl Jung, which is known as analytical psychology, was used to integrate the object relations and positive psychology approaches. The object relations approaches used in the study include the work of Donald Winnicott and Melanie Klein. Positive psychology theorists include William Compton and Martin Seligman. This study also

attempts to look critically at these theories and attempts to address the difficulties associated with studying African culture from a Western perspective.

1.7. BRIEF DISCUSSION OF THE FOLLOWING CHAPTERS

While Chapter one provided a brief introduction to this study, Chapter two provides an introduction to the field of mental health with regards to HIV/AIDS. Chapter two also includes a literature review on relevant themes that emerged from the data, such as death, grief and shame. Chapter three contains a discussion on the theoretical approaches to be used in this study. Chapter four presents a description of the research process of this study. It provides information concerning the research method used and the various stages of the research process. Chapter five introduces the participants and attempts to provide a context for their lives, opinions and experiences. In Chapter six the results of the study are presented. Although certain interpretation by the author was unavoidable during the analysis of the data, very little theory is attached to the data at this stage in order to present the results in a manner as close to the lived reality of the interviewees as possible. Chapter seven integrates the findings of the study and attaches relevant theory. The final chapter, Chapter eight, concludes and critiques the study and provides recommendations for further study.

CHAPTER TWO

LITERATURE STUDY

Every problem, therefore, brings the possibility of a widening consciousness.

C.G. Jung

2.1. INTRODUCTION

As levels of HIV infection have risen, the last two decades have seen a proliferation of research into HIV/AIDS, mostly in the areas of treatment and prevention. Although the last decade has seen a shift to include more on the psychological sequelae of the illness, the vast majority of this research has had a pathogenic focus. Many studies have linked depression to higher levels of distress and disability (Olley, Seedat, Nei & Stein, 2004), as well as to dysfunctional coping styles (Commerford, Gular, Orr, Reznikoff & O' Dowd, 1994), finding interdependent relationships between them. In line with current international trends, a portion of this research has begun to focus on the virtues and strengths that assist people to cope with HIV infection and its implications for their lives.

While reviewing the literature on the psychological impact of HIV/AIDS, this literature study also briefly explores the role of gender and the implications of this on the experience of HIV-positive individuals, and the influence of socio-economic circumstances on coping. A variety of studies have been done in the area of gender within a cultural context and look at role expectations and the influence this has on the prevention of HIV infection, the course and impact of the illness, access to treatment and support, and the consequences of death on dependents (Rohleder & Gibson, 2006; Soskolne, Stein & Gibson, 2004). These studies have explored gender within the context of cultural background with regards to HIV/AIDS, with a specific focus on issues such as gender roles and the disempowered position of women in the black and coloured communities.

2.2. HIV/AIDS AND MENTAL HEALTH IN CONTEXT

2.2.1. The impact of HIV/AIDS on mental health and coping

Evidence from a meta-analysis of the relationship between HIV infection and risk for depressive disorders suggests that major depressive disorder is a common psychiatric

complication of HIV/AIDS, with some studies finding up to a 47,8% prevalence rate (Clesla & Roberts, 2001). Furthermore, studies into the association of coping styles and depression in HIV/AIDS have found a consistent relationship between depression and dysfunctional coping styles, such as denial (Commerford et al., 1994). HIV/AIDS has been shown to be accompanied by a substantial impairment in social and occupational roles as well as in physical functioning at both the early and later, symptomatic or AIDS-defining stages (Wachtel, Piette, Mor, Stein, Fleishman & Carpenter, 1992) and later studies have suggested a relationship between such disability and major depression in HIV-positive patients (Olley et al., 2004). However, the symptomatic stage of HIV infection has been shown to be associated with a higher prevalence of depressive symptoms (Maj, 1997; Clesla & Roberts, 2001). The course of the illness also plays a role: "Some patients may experience severe distress at the time they learnt about HIV infection, with distress diminishing after a period of adaptation to the diagnosis. Distress may increase again with the onset of HIV related symptoms or with an AIDS diagnosis" (Olley et al, 2004, p.482). Even the treatment for HIV infection has been linked to depression:

In the AIDS Weekly (2002) it was reported that more than 80% of HIV positive patients reported symptoms of depression and anxiety. The report states further that although the psychiatric causes are many and include factors such as the direct central nervous system (CNS) effects of HIV, CNS opportunistic infections and street drugs, the majority of physicians surveyed believed that HIV medications (antiretrovirals) are a leading cause of their patients' most common mental health problems (84%) (Freeman, 2004, p.144).

Inversely, a relationship between baseline depression scores based on depressive symptoms and accelerated rate of CD4 decline has also been reported in a 5.5 year follow-up study (Burack, Barrett & Stall, 1993), suggesting that depression levels influence immune functioning i.e. that higher levels of depression may play a role in increasing disability or even shortening lifespan.

Thus, it appears that coping styles, levels of disability and depressive symptoms appear to have an interdependent relationship, highlighting the relevance of this study in terms of facilitating a better understanding of coping with HIV/AIDS in order to prevent higher levels of depression and disability.

2.2.2. Gender, socio-economic status and HIV/AIDS

There are a number of clear differences in the experience of living with HIV that emerge when gender is considered. Cederfjall, Langius-Eklof, Lidman and Wredling (2001) found that women with HIV tend to perceive less well-being, irrespective of disease staging, a lower Sense of Coherence and a lower health-related quality of life than HIV-positive men. However, the influence of gender in the realm of this illness is far wider. According to Wilton (1997) the AIDS epidemic is a 'gendered epidemic'. "Studies indicate that women are economically, psychologically and socially dependent on men, and this directly influences the way in which AIDS affects women" (Hoosen & Collins, 2004, p.487). According to Rohleder and Gibson (2006) "In South Africa, black women generally occupy the lowest rungs on the hierarchy of social, economic and political power" (p. 27). The majority of traditional African societies are patriarchal, with men holding the decision-making power (Macheke & Campbell, 1998). This unequal power and lack of status and rights, especially with regards to sexual activities, have placed women at more risk of infection, together with the 'feminisation of poverty', which is the process whereby poverty seems to impact more on women, placing them at greater risk of infection. In some cases, in order to meet their basic needs and the needs of their family members, women need to engage in transactional sex (Ankrah & Long, 1996). Furthermore, women who are dependent on regular or multiple partners for financial survival are less likely to insist on safe sex for fear of jeopardizing these relationships (Strebel & Lindegger, 1998).

According to Shefer, Strebel, Wilson, Shabalala, Simbayi, Ratele, Potgieter and Andipatin (2002) gender issues play an integral role in the construction of deviance and promiscuity, for example, a man with many sexual partners is considered more of a man, while a woman with the same number of sexual partners is considered dirty. In some communities, women are regarded as dirty and carriers of HIV and other sexually transmitted diseases (Shefer et al., 2002). Hence, South African black women with HIV are perceived as being dirty, deviant, damaged and diseased and are subjected to multiple forms of stigmatization (Rohleder & Gibson, 2006; Lawless, Kippax & Crawford, 1996).

Socio-economic status and gender have also been found to have a relationship to the prevalence of depression in HIV-positive patients in both the United States of America and South Africa. Links between gender roles, HIV/AIDS and depression have also been found. A lower socio-economic status has been associated with a higher prevalence of depression (Moore, Schuman & Schoenbaum, 1999) and female gender has been found to be associated with a higher risk for major depression (Lichtenstein, Laska & Clair, 2002; Olley et al, 2004). These findings are particularly relevant to the South African situation where the majority of people infected with HIV are women in lower socio-economic circumstances (Hartnell, 2005). This highlights the importance of the issues of gender and poverty within the field of HIV/AIDS research and management. According to an article in the Economist (27 November 2004) economic inequality between the sexes and lack of education contribute to the transmission of HIV to women:

> In general, the less educated a woman is, the greater risk she will contract HIV…to fight the disease, one has to understand how it spreads. And one of the most striking aspects of the virus' passage from male to female bloodstreams is how little say women have had in the matter. Men tend to contract HIV because of things they have done; women are more likely to contract it because of things that have been done to them (Economist, 27 November 2004, p. 82).

Women also commonly fulfill roles as caregivers and this puts them at risk for higher levels of distress. According to Freeman (2004):

> Looking beyond the numbers and prevalence rates, there are numerous factors that make certain HIV-positive people particularly vulnerable to mental health problems. For example, HIV-positive people are often themselves caregivers. In South Africa, there are more women than men who are HIV-positive (Shisana & Simbayi, 2002), and it is women who almost always fulfill the care-giving role. This exposes them to additional stressors. Indeed, not only do HIV-positive women find it difficult to look after their own health adequately (Walker, 2002), but they may experience deep feelings of guilt and worry at leaving their dependents behind when they die. It is well documented that women will often see to the needs of their partners and their children before looking after themselves (Goosen & Klugman, 1996) (p. 148).

According to Shisana and Davids (2004) correcting gender inequalities is central to controlling HIV/AIDS. Exploration of gender issues is vital to understanding how HIV is spread and how the various mental dimensions of the disease are handled. "Women must be protected if the AIDS epidemic is to be checked. It is therefore essential for governments to implement gender-sensitive policies" (Shisana & Davids, 2004, p.812). According to Walker, Reid and Cornell (in Rohleder & Gibson, 2006) "…in order to understand South Africa's spiraling HIV/AIDS epidemic, the role of gender, sex and power needs to be examined" (p. 27). Stone and Gosten (2004) advocate using human rights to combat the HIV/AIDS pandemic, stating that:

> The HIV/AIDS pandemic presents a stark example of the nexus between human rights and health…As the pandemic has progressed, it has become apparent that human rights law is relevant not only to the treatment of infected individuals but also to the wider policies that influence

HIV/AIDS, as populations that are discriminated against, marginalized, and stigmatized are at a greater risk of contracting the disease (p. 2).

2.2.3. HIV/AIDS and social support

Compton (2005) provides a definition of social support and states that it "can include emotional support such as caring and empathy, getting positive feedback about our behaviour, receiving helpful information, the willingness of others to give us their time or other tangible forms of assistance" (p. 112).

Studies conducted with HIV-positive women in Khayelitsha in the Western Cape, found that individuals who had participated in therapeutic interventions as a source of support were found to be more optimistic and more able to reject the effects of HIV/AIDS stigma on their identity and sense of self (Rohleder & Gobson, 2006). This study highlights the importance of social support with regards to coping with HIV, living positively and resilience.

Social support as a concept and its importance with regards to coping will be discussed in more detail in Chapter Three of this study. This section will however, attempt briefly to explain the difficulties around accessing social support that HIV-positive individuals experience. Due to the stigma associated with HIV/AIDS many HIV-positive individuals attempt to hide their status and rather try to 'pass as normal' (Alubo, Zwandor, Jolayemi & Omudu, 2002), which implies not disclosing their status and thereby having limited access to various forms of social support. According to Meursing and Sibindi (in Rohleder & Gibson, 2006): "Many HIV-positive individuals do not disclose their status to others, resulting in the patient being unable to find social and family support, thereby aggravating their sense of helplessness and loneliness" (p. 27).

France (in Rohleder & Gibson, 2006) conducted a study into the contexts in which HIV-positive individuals experience the highest degree of stigma and shame and the two most

cited contexts were the public health care setting and the family. The fact that the two settings where support and lack of judgement should be the most forthcoming were cited as being the most likely source of stigmatization demonstrates the difficulty HIV-positive people experience accessing much-needed social support.

According to Compton (2005) a variety of studies have found that social support has a positive impact on well-being. Perceiving oneself as having sufficient social support has been linked to higher self-esteem, more effective coping, better physical health and fewer psychological problems. According to Compton (2005) studies have shown that when individuals seek out social support they are likely to experience increased optimism and more perceived control. It is thus easy to see the detrimental effects that HIV/AIDS stigma and the resulting reluctance of HIV-infected individuals to disclose their status has on these individuals' opportunities to receive social support. An American study conducted by Goggin, Catley, Brisco, Engelson, Rabkin and Kotler (2001) asked HIV positive women what advice they would like to give other women and the most frequent suggestions given were to maintain a positive attitude, create a support system for oneself and take care of oneself. According to Goggin et al., (2001) "with regard to awareness of a limited life span, alienation, and stigma, the women's responses may indicate how important HIV resources can be in providing social support, reducing alienation, and fostering empowerment" (p. 87).

According to Koopman, Gore-Felton, Marouf, Butler, Field, Gill, Chen, Israelski and Spiegel (2000) the literature around HIV/AIDS indicates three main factors influencing the degree of perceived stress experienced by HIV positive individuals, namely, the use of coping strategies, attachment style and perceived social support. Their study found that individuals with more anxious or insecure attachment styles tended to experience significantly greater levels of emotional distress. Koopman et al. (2000) hypothesized that a reason for this may be that

> …individuals with insecure or highly anxious attachment styles are
> more likely to perceive their lives as stressful, they may consequently

be at higher risk for under-utilizing or alienating available social support…perceived stress is likely to be greater among persons having a highly anxious attachment style because their hypervigilance in interpersonal relationships leads to misinterpreting others' behaviours as rejecting or critical towards them. Also, their perceived stress is likely to be exacerbated by having their resolute attempts to experience greater closeness actually met with rejecting and critical behaviour from others (p. 669).

While this study highlights the important role of attachment style in accessing social support, it once again demonstrates how the stigma surrounding HIV/AIDS makes it more difficult for HIV positive individuals to access social support.

2.2.4. HIV/AIDS and resilience

According to Compton (2005) early theories of child development hold the basic assumption that a dysfunctional family environment can lead to a less healthy personality development into adulthood, however, recent studies have suggested that "poor early environments do not necessarily result in psychological problems for the children as adults" (Compton, 2005, p. 151). According to Anthony (in Compton, 2005) a surprising finding has been that some children from difficult home environments can turn out to be quite well-adjusted as adults. According to Compton (2005):

> These studies are relatively consistent in finding a group of children
> who thrive in spite of difficult backgrounds that include chronic
> poverty, parental neglect, parental psychopathology, abuse, and
> living in the midst of war. However, these findings should not be
> taken as evidence that early family environments are unimportant –
> they are extremely important. Rather, these findings point to the fact

that some children learn how to adjust to the difficult environments

and are less affected than other children (p. 152).

Werner (1995) states that the ability that some children possess, which enables them to 'bounce back' and do well despite a life of adversity has come to be known as resilience. Resilience can be defined as "a pattern of positive adaptation in the face of significant adversity or risk" (Masten & Reed, in Compton, 2005, p. 152). While Werner (1995) found that approximately one third of children from difficult home environments were resilient and developed into competent and caring adults, Anthony (in Compton, 2005) found that approximately 10 percent of children from schizophrenic parents developed into well-adjusted adults despite difficult home environments.

Werner (1995) described a number of characteristics of resilient children. The first of these is that resilient children are able to emotionally detach themselves from unhealthy attachment figures and find suitably nurturing 'surrogate' parental figures. This ability was linked to the fact that these children generally have a temperament that is "active, affectionate, cuddly, good-natured, easy to deal with" (Werner, 1995, p. 82). Werner (1995) also found that these children tended to develop a close relationship with at least one teacher, which served them as a good role model. The second characteristic of resilient children that Werner (1995) describes is that they tend to have good social and communication skills. The children in her study tended to have at least one close friend and the desire to nurture and help others. The third characteristic of resilient children is that they tend to have hobbies which serve as creative outlets and a means to experience a sense of competence and mastery. The fourth characteristic was a sense of optimism. Resilient children hold the belief that life will somehow work out okay. Werner (1995) found that resilient children tend to have an internal locus of control and a positive self-concept and that they are able to balance a sense of autonomy with the ability to ask for appropriate assistance when necessary. The last characteristic that Werner (1995) identified was that of religious beliefs. Her group of resilient children tended to originate from families that held a set of religious beliefs that provided a sense of meaning for these children when times were difficult.

Werner (1995) also found a number of factors that served as protective buffers against pathological development due to dysfunctional home environments or parental pathology. These buffers tended to differ for male and females. Whereas resilient boys tended to originate from homes with an appropriate amount of structure and tend to encourage emotional expressiveness, resilient girls tended to originate from homes that encourage independence and risk-taking. Resilient girls also tended to have experienced at least one older female figure as being reliably supportive. A mother who was steadily employed also featured as having a significantly positive influence on girls' development. Werner (1995) found that these buffers were significant across ethnicity and social class.

Hence, resilience seems to be the ability to actively detach from unhealthy attachments and seek out nurturing relationships, the desire to nurture others and the ability to find situations that reinforce a sense of competence. It is surmised that a sense of resilience developed in childhood is incorporated into the development of resilient adult coping styles, which according to Werner (1995) includes a sense of flexibility in that independence and autonomy are valued alongside social support.

The characteristics of resilience can also be seen in adults. In a study conducted to ascertain the lived experience of HIV-positive African women living in the United Kingdom, an emphasis on the theme of protection was also found in that most of the women reported feeling the need to protect themselves and their loved ones from physical and emotional harm. This was often achieved through the creation of more secluded lives and the avoidance of intimate relationships. However, some of these women also described how living with HIV and its associated problems had given them additional insight. Many described feeling 'closer to God', 'more courageous', 'more mature', and more grateful for what was 'precious' (Anderson & Doyal, 2004).

> The findings from the study have highlighted amazing resilience in the face of what are often extremely difficult circumstances. Recognition of this reality needs to be the starting point for both

future research and for the planning of services to meet the needs of HIV-positive women from Africa (Anderson & Doyal, 2004, p.104).

2.3. HIV/AIDS, IDENTITY, CULTURE AND STIGMA

2.3.1. Theoretical and African conceptions of self

A discussion on the notion of self is required due to the fact that studies have found that many women report a change in their sense of self after receiving an HIV positive diagnosis (Goggin, Catley, Brisco, Engelson, Rabkin & Kotler, 2001; Anderson & Doyle, 2004). The fact that the women in this study were African implies that a discussion on African conceptualizations of self would also be useful. This section will aim to discuss both the tension between modern and postmodern conceptualizations of self as well as definition of self when considered from Western and African perspectives.

2.3.1.1. A modern versus postmodern self

There is a great deal of tension that exists theoretically in terms of a definition of the concept of self. While modern theories tend to assume a self that is to some degree biologically determined, post-modern approaches tend to view the self as developing through discourse:

> Whereas analytical psychology pertains to intra-individual dynamical structures, which could be externalized in dreams, visions, myths etc., social constructionism pertains to supra-individual power structures, immanent in discursive practices, which are internalized in people's 'private' discourse e.g. in one's thoughts about oneself (Jones, 2003, p. 359).

The argument about a definition of self seems to originate from postmodern criticisms of the modern assumptions about a self that develops along with the body and that is assumed by psychoanalytic theories to consist of conscious and unconscious elements. Social constructionists argue that the notion of an unconscious is no longer rational and assumes causal powers that do not exist (Varela, 1995). However, according to Jones (2003), while social constructionism may have cast doubt on "psychologists' ability to infer the 'natural function' of human beings – that is, natural function in the Aristotelian sense of prospering through personal development towards an ideal state…" (Jones, 2003, p. 359) through the observation that "…much of what is taken to constitute selfhood – could be shown to originate in language-enabled processes" (Jones, 2003, p. 359), this view may be a little extreme, as so far, social constructionism has not provided an alternative theory that considers the body (Jones, 2002). According to Jones (2003):

> The locus of most tension seems to be the conception of the
> relation of selfhood to body. From the critical [post-modern]
> perspective, agency is a disembodied social construction invested
> with the corporal body of the child who is instructed how to talk,
> walk, and act like a 'man'. Power relations do not originate in
> the body but subjugate it (p. 365).

This 'Foucauldian' view of the body stands in opposition to the modern view that the body implies that "one is involved in a definite environment, because our body is our vehicle for being in the world…the medium for having a world and interacting with it…the body is a point from which space radiates and around which things arrange themselves in an orderly way" (Olsen, 2000, p. 96).

Thus, while psychodynamic and psychoanalytic approaches hold the view that each person's self has agency that is separate (although influenced by) from societal discourses and that can organize and structure their inner, personal experience, the social constructionist approaches hold "a view of persons as organizing and structuring their experience only through the discursive practices of their communities – viewing

psychology itself as a cultural discourse" (Jones, 2003, p. 361). These two opposing views of self are also discussed by Quackenbush (2005) who states that considering culture when studying human behaviour adds a complexity as it brings with it an imperative to justify actions and which implies an element of value. Hence the concept of self can be considered dual and it is important to distinguish the "truths that are revealed at the levels of matter, life and mind" from the "value-contingent truths that emerge at the level of culture" (Quackenbush, 2005, p. 69). This is explained in more detail:

> …this cultural demand for justification brings into being a "self" that is at once a fact (insofar as "I am what I *do*") and a value (insofar as "I am what I can *justify*"). As an unstable (or metastable) synthesis of facts and values, the cultural-person-as-a-whole can never find adequate grounds for self-unification on a purely empirical plane. Thus, a holistic, person-centered psychology requires a conceptual analysis of the relationship between scientific discovery *and* the creative acts that bring selves, values and communities into being (Quackenbush, 2005, p. 69).

In the extreme, social constructionists claim that there is no psychological reality outside discourse stating that "selves emerge from complex bodies of knowledge that are organized like oral stories…in which the indexical commitments of the speakers differ throughout the discourse" (Van Langenhove & Harre, 1993, p. 94). However, Quackenbush (2005) comments that "after nearly two decades of sustained interest into personal narratives on the part of personality and developmental psychologists …the thesis that the self is best understood as a story has become a well-worn cliché" (p. 72) and states that "the adoption of a scientific mindset does not in-itself stand opposed to the observation that people tell stories" (p. 75).

Instead, Quackenbush (2005) proposes a metatheoretical 'perch' that does not attempt a synthesis of the two approaches, "which masks over the tensions" (p. 78), but rather

appreciates the value that both approaches bring to the study of human behaviour at different levels. While the modern approach "can be granted epistemic authority at the levels of matter, life and mind simply by virtue of its success…Truth at a cultural level of analysis, however, remains contingent upon the sociolinguistic justification systems that illuminate the moral significance of each of our acts" (p. 78). Jones (2003) also writes about "The middle ground between these contrasting viewpoints" (p. 365) and states that this middle ground could be "not a new content in terms of yet another theoretical model – but the ability to see how the contradictory positions might complement each other" (p. 365). Jones (2003) states that while psychodynamic and psychoanalytic approaches hold to the belief that there are natural laws for becoming human and are "concerned with how acts organize themselves in actors' phenomenological fields" (p. 366), social constructionism holds that there are cultural codes for becoming a person and are concerned with "how discursive practices make actors accountable for acts" (p. 366).

Discussing a Jungian analytic perspective in particular, Jones (2003) states that at certain levels there are similarities between Jung's view of self and that of the postmodern approaches. In particular, she draws attention to the Jungian notion of the "Hero's Journey", which is equated to the analytic concept of individuation, and its focus on development as narrative". Jones (2003) states:

> Looking beyond the opposition between the two positions on
> human nature [and the concept of self, by implication], they
> might transpire as the same dance to different tunes. Both
> concern continuities and discontinuities of human life at the level
> of the person and personal meaning, rather than statistical
> regularities at the level of aggregates or reduction to performance
> in experimental procedures. In so far as Jungian psychology
> coincides with the postmodern…there are also parallels between
> Jung and postmodern psychology (p. 367).

However, Jones (2003) is also aware that in important ways, modern and postmodern approaches are different. While social constructionism attributes the connections between meaning, power and knowledge to language (Parker in Jones, 2003), Jung attributes these connections to the "'symbolic attitude', which is the function of a solitary consciousness (Jones, 2003). Jung (1921) states that the individual's consciousness "assigns meaning to events…and attaches to this meaning a greater value than to the bare facts" (p. 819). In this instance, it can be seen that Jung did not give sufficient attention to the influence of social and cultural discourses on the meanings that people give to events or others. However, according to Jones (2003):

> …some analytical psychologists today strive to redress Jung's understatement of the intersubjective construction of meaning, at both practical and theoretical levels…in Bovensiepen's redefinition, the symbolic attitude transpires as enabled through social interaction. Similarly, some social constructionist's grapple with the understatement of the bodily lived experience: 'the way in which our immediate, bodily reactions necessarily relate us to our surroundings, has remained rationally invisible to us' (Shotter, 1998, p. 34) (p. 366).

In other words, there is an appreciation of the notion that 'self' may be both a biological 'bodily experience' as well as a construct that is created in the intersubjective space between people. Commenting on the differences between analytic psychology and postmodern approaches, Jones (2003) states:

> However, letting the tensions play on, there is a level at which they are *not* saying (more or less) the same thing. Rather, the relationship between the analytical and the critical now seems that of yin and yang. What visibly constitutes the one is hidden, concealed as an unvoiced necessity, inside the other, and vice versa (p. 367).

Jones (2003) proposes that both modern and postmodern approaches hold value and are necessary for a fuller understanding – an understanding that takes both biology and context into account. Jones (2003) states that in "discursive mediation of the child's experience, the living body drops from sight" (p. 364), in that there is a focus on the interpersonal space between people, and identity is seen to originate from society's discourses about power, gender and individualism, "rather than in any inner upsurge for autonomy" (p. 364) . However, according to Jones (2003) concealed in any explanatory narrative from a social constructionist perspective: "…there is the necessity of the flesh and blood. This means not only being equipped with senses and brain, but also predisposed to position oneself in relations of power and relations of belonging" (p. 365). In other words, while societal discourses influence experience and social positioning, the brain also has a role to play in that its sensitivity to affect associated with the experience of some objects and not others, predisposes a person to be more or less influenced by certain societal discourses. "…the living body is seen as centering itself in its environment, investing interest in certain objects, both material and social, and making his relation to these consciously accessible by means of symbolic activity" (Jones, 2003, p. 365). Like Quackenbush (2005), Jones (2003) appreciates that there are certain levels where a synthesis of modern and postmodern approaches would be undesirable, just as Jung's concept of 'psychic energy' is based on the principle of opposites and the tension between them as necessary for creative achievement.

2.3.1.2. A Western versus African self

The concept of self can be said to be an entirely Western notion and much debate has ensued over whether a Western definition can be applied to an African context. African world views tend to see an interconnection between people and between humans and nature. According to Kagame (in Jahn, 1990) basic African ontology consists of four categories and an overriding joining principle. These four categories are: Muntu, which is the category for human beings and the plural of which is Bantu; Kintu, which is the

category for things or objects, both animate and inanimate, the plural of which is Bintu; Hantu, which is the category for place and time; and Kuntu, which is the category for quality, style, rhythm and beauty. According to African world views all these categories are forces and considered universal categories of existence. All things are seen as interconnected as is expressed through their names and this interconnection is known as NTU. Jahn (1990) writes that NTU is "simply existence, universal and particular. It is at once 'God' and man and thing and time and space and modality. NTU is everywhere and everything" (p. xx). Hence, the traditional African self is seen as interconnected.

Research has tended to make a distinction between cultures that are individualistic and view the self as a separate entity and cultures that are regarded as collectivist and view the self as connected to others (Eaton & Louw, 2000; Compton, 2005), however, recent writers in African studies have begun to object to the notion of African cultures as collectivist and to "characterizations of an African self that imply the collectivist variety of interdependence" (Adams & Dzokoto, 2003, p. 347) as this implies loss of personal identity in the collective and a case of Western 'othering' (Shaw, 2000). According to Adams and Dzokoto (2003) considering African cultures as collective seems to be "more a projection of Western categories than a reflection of the constructions of self that prevail in African settings" (p. 347). Instead of the term collective, studies on African notions of self or identity have referred to an "interdependent self" (Markus, Mullaly & Kitayama, 1997), a "relational self" (Piot, 1999) or "relational individualism" (Shaw, 2000). According to Adams and Dzokoto (2003) Western constructions of self tend to:

> …frame connection as a secondary product, not necessarily in
> the sense of being less valued, but in the sense of being derived
> or manufactured. Rather than a default act of existence, these
> constructions regard connection as voluntary and often tenuous
> arrangement of more basic, individual selves (p.346).

In contrast, African conceptualizations:

> …tend to regard selves as fundamentally connected – not only to other people (both living relatives and dead ancestors), but also to place, spiritual forces, and a sense of built-in order….Rather than internal properties of bounded entities, these constructions locate self and identity in pre-existing fields of relational force (Adams & Dzokoto, 2003, p. 346).

It is important to note that a number of assumptions are made about the African concept of self as connected or interdependent. For example, the description of an African self that is 'connected' does not imply a "diffusion of that self into a deindividuated collective" (Adams & Dzokoto, 2003). In other words, an African concept of self as interdependent does not mean that the entire experience of self is that of being connected to others, instead there is a self that is distinct but with an "inherent, inescapable connection to larger fields of relational force" (Adams & Dzokoto, 2003).

Another assumption that that is often made about the connectedness of the self implied in an African world, according to Adams and Dzokoto (2003), is that an 'interdependent self' is often associated with "a prosocial orientation or communal harmony" (p. 346), which disregards the tendency in African settings to "emphasize the "risks and dangers" of inherent interdependence" (p. 346). One of these risks is the possibility of enemyship (Adams & Dzokoto, 2003). According to Riesman (in Adams & Dzokoto, 2003):

> In thinking of so many African peoples, almost all misfortune is caused by people with whom you have some relation…The common African understanding of the person, which carries the self as connected to forces and entities outside it, carries considerable risks and dangers of its own (p. 346).

Hence, enemyship can be considered to be a part of the experience of interdependence. While this inherent connection to a larger relational order can have positive aspects, like the availability of support and a decrease in feelings of loneliness, it can also have negative aspects, like an increase in interpersonal friction (Adams, 2000).

Kelley (1997) writes about 'interdependence theory', which is how an interdependent self can be viewed as developing in relation to an everyday world that is structured around interdependence, for example, sharing small living spaces, sharing bowls etc. In other words, there is a "recognition that material structures of interdependence afford mental structures of interdependence" (Adams & Dzokoto, 2003). This theory points to the importance of taking cultural variations into account, in that the variations in the experience of interdependence of everyday life influences the extent to which the self is viewed as relational.

Kelley's (1997) interdependence theory is important with regard to this study as the participants in this study seemed to exhibit notions of self that included both a relational sense of self as well as a more 'Western' individualistic sense of self. While there was a tendency to include relationships with others when discussing personal experience that was noted in the participants' descriptions of their experience, it was also evident that the participants, at other times, tended to view themselves as separate individuals. Many of them placed value on autonomy, independence and self-reliance. While the participants embraced their cultural practice of caring for their parents, they also questioned the roles assigned to them by these cultural traditions. Thus, the participants of this study appear to be straddling two cultures – an individualistic Western culture as well as a collective African culture. This may be as a result of increasing 'Westernization' of African cultures in urban areas, however, the reasons for this are not within the scope of this study and it is sufficient to merely acknowledge the perspective from which these women are speaking.

2.3.2. Gender and identity

According to feminist writers, historically, women's selves, identities and positions in society "have been undermined by attempts to define their 'unstable' bodies as both dominating and threatening their 'fragile' minds" (Shilling, 2003, p. 40). This view of women originated in the 18th Century and can be seen even in the history of psychology. According to Shildrick (1997):

> …in being somehow more fully embodied than men, women have been characterized simply as less able to rise above uncontrollable natural processes and passions and therefore disqualified from mature personhood…it is as though bodies could somehow interfere with moral thought, instructing the mind, rather than the other way round as is the case with men (p. 26).

A woman's body seems to have become the battlefield where women fight for liberation: "It is through her body that oppression works, reifying her, sexualizing her, victimizing her, disabling her" (Greer, 1999, p. 114). For decades, feminists have been fighting to reclaim women's bodies and minds from these stereotypes (Fernandes, Papaikonomou & Nieuwoudt, 2006), seeing embodiment as a process and not a split between body and mind (Shildrick, 1997) and showing that experiences of embodiment are essential for a healthy functioning of the self (Castle & Phillips, 2002). According to Macdonald (1995) the body is considered an integral part of a woman's identity formation and the perceptions she holds regarding her physical appearance are usually complex and influenced by genetics, societal discourses regarding 'ideal appearance' and the woman's particular personality style. According to Freedman (in Fernandes et al., 2006) "It is a woman's body image that ultimately determines how she sees and experiences herself and others" (p. 852).

According to Cromby and Nightingale (in Fernandes et al., 2006) a woman's body is particularly associated to her identity due to the facts that it is a "site of birth, growth,

aging, and death, of pleasure, pain and many things…an object of desires…a bearer of features…a biological machine that provides the material preconditions for subjectivity, thought, emotion and language…" (p. 853). Hence the distortions of shape and bodily functioning that are characteristic of illnesses, such as AIDS, tend to be a crisis in terms of threatening a woman's very identity and sense of self. As well as being a threat to life itself, AIDS can threaten physical appearance and the ability and/or practicality of bearing children, which brings a number of social stigmas to bear. According to Shildrick (1997) women who view themselves as being 'disabled' may experience a threat to their self-identity and then find their bodily experience invalidated. According to Fernandes et al. (2006) "A search for psychological and spiritual wholeness will emerge from these particular life crises. These turning points almost always raise fundamental questions about oneself and are instrumental in redefining a woman's self-identity in relation to the way in which she perceives her purpose and value in life" (p. 853). Hence, it can be seen that HIV/AIDS may necessitate a redefinition of identity for many women.

2.3.3. Culture, religion, stigma and HIV/AIDS

According to Manganyi (1981): "…culture is symbolization, ritual, intersubjectivity, in terms of which shared meanings and significances are attributed to a shared universe…culture is a medium for human self-extension and transcendence – a kind of symbolization which has a lot to do with the notions of individual and group identity" (p.65). According to Fife and Wright (2000) stigma is a 'central force' in the lives of HIV-positive individuals. Stigma can be defined as having an attribute that is considered deviant or different by society and that is experienced as deeply discrediting and spoiling one's identity (Goffman, 1963). Stigma has also been described as a means by which society wields its power in terms of defining what is and what is not acceptable or desirable. By defining something as deviant or undesirable and excluding those decided to be deviant or undesirable, society is able to exercise its power (Gilmore & Somerville, 1994). A definition of AIDS-related stigma is "prejudice, discounting, discrediting and

discrimination directed at people perceived to have AIDS or HIV and individuals, groups and communities with whom they are associated" (Herek, 1999, p. 1102).

In a national household survey it was found that 26% of those surveyed would be unwilling to share a meal with an HIV-positive person, 18% would be unwilling to sleep in the same room with someone with AIDS and 6% would not talk to someone with AIDS (Shisana & Simbayi, 2002). Although these percentages seem low, Stein (2003) criticized the study, stating that the quantitative, questionnaire method measures self-report and not actual incidence of HIV/AIDS discrimination and stigmatization, and that therefore it cannot be considered an accurate measure of stigma. According to Visser, Makin and Lehobye (2006):

> HIV/AIDS stigma is a complicated issue with deep roots in the domains of gender, race, class, sexuality and culture. Although it is difficult to understand the process by which stigma is developed or changed on a community level, the clear need for establishing stigma-curbing interventions in the South African community cannot be denied. In addition to the counseling and education of HIV positive individuals to reduce their own fear of discrimination, interventions are needed on the community level, such as the implementation of Human Rights laws, the provision of social and healthcare services and social action campaigns to address the public's negative attitudes towards and perceptions of HIV/AIDS. This would contribute towards changing the context within which individuals and communities respond to HIV/AIDS (p. 55).

AIDS-related stigmas that permeate certain sectors of the South African population have been reported to be the greatest obstacle to HIV prevention and care (UNAIDS, 2003) due to the fact that the fear associated with HIV/AIDS stigma prevents many people from testing, disclosing their status or attending clinics for treatment and support (Kalichman

& Simbayi, 2004). "Stigmas are linked to discrimination and therefore pose a realistic barrier to engaging in HIV-testing and prevention" (Parker & Aggleton, 2004, p. 14). According to Kilewo, Massawe, Lyamuya, Semali, Kalokola, Urassa, Giattas, Temu, Karlsson, Mhalu and Biberfeld (2001) the primary reason for not disclosing HIV/AIDS status and seeking treatment, amongst HIV-positive sub-Saharan women, is fear of AIDS stigma. Sontag (1991) states that HIV carries the greatest stigma and "capacity to create a spoiled identity" (p. 101) than any other illness or disease.

Underlying this stigma, in many cases, are beliefs associated with Western religious ideas of immorality and punishment or traditional African belief systems. While some conflict exists between traditional African beliefs and Western religions brought to Africa during colonialism, for the most part, these religions appear to have been integrated into current African culture (Eskell-Blokland, 2005). According to Masolo (in Eskell-Blokland, 2005) this 'accommodation' of the newer religions most likely occurred as adaptation to the pressures of Westernization. Eskell-Blokland (2005) writes that in the traditional African worldview, daily life intertwines with the spiritual and according to Masolo (in Eskell-Blokland, 2005) traditional African thought process remains for the most part undisturbed by new scientific explanations and has been referred to as a "world of magical beliefs" (p. 129). Eskell-Blokland (2005) states:

> For the traditional African the identification of words with reality
> opens a window to the magical, the spirit world and personal
> spiritual explanations…this is typical of the dynamic at play in some
> African traditional ceremonies…and in the significance of the role
> of spirituality in the African traditional way of life (p. 107).

Hence, according to Goba (in Eskell-Blokland, 2005) the present day African Independent Churches tend to be a combination of both Christian and African spiritual traditions, offering physical and mental healing and connection with the ancestors. According to Eskell-Blokland (2005) "The social power and authority held by the

churches of Africa testify to the important place spiritual life plays in traditional and modern African culture beyond the narrow delineation of religion" (p. 108).

A common traditional African belief is that HIV/AIDS is a result of supernatural or spiritual forces (van Dyk, 2001). This belief is prevalent in many traditional African cultures, with results from studies showing that up to one in three black South Africans either endorses the belief that HIV/AIDS is caused by spirits and supernatural forces or is not sure (Kalichman & Simbayi, 2004). Some of the stigma around HIV/AIDS originates in traditional African belief systems of health and disease, where it is often thought that ancestors, witches and God are the ultimate cause of illness (Sow, in Kalichman & Simbayi, 2004). If a person has angered an ancestor or God, illness may be sent or protection from illness withdrawn, resulting in sickness (van Dyk, 2001). According to Kalichman and Simbayi (2004), the belief that AIDS comes from a spirit is reinforced by the fact that within a group of people leading similar lifestyles, only some become infected.

The religious beliefs that have been associated with HIV/AIDS stigmas, include HIV being considered as evil and sinful and AIDS being considered to be a plague (Sontag, 1991) or as resulting from deviance (Joffe, 1995). "Attributing the cause of AIDS to ancestral spirits or an angry God leads directly to stigmatizing beliefs about people with HIV/AIDS as they have surely brought the condition upon themselves and their community" (Goffman, in Kalichman & Simbayi, 2004). Gilmore and Somerville (1994) found that HIV and AIDS is associated with punishment, death, horror and otherness and that HIV sufferers are seen as villains. According to Rohleder and Gibson (2006): "These metaphors become part of the language used to discuss and understand HIV and are used to make representations of 'others' who are infected and the 'self' who is not infected" (p. 26). Although studies have found these beliefs more prevalent amongst rural Africans with less access to education and HIV/AIDS knowledge, even well-informed and well-educated professionals have been shown to harbour AIDS stigmas (Brown, MacIntyre & Trujillo, 2003).

According to theoretical literature, these social roots of stigma result from both the fear of physical contagion as well as symbolic contagion or threat to the status quo (Parker & Aggleton, 2003). HIV is a frightening reality and the fear of infection is anxiety provoking. Psychodynamically, behaviours in humans are understood as attempts to alleviate or defend against anxiety. According to Joffe (1999) stigma surrounding HIV/AIDS can be understood as a defense against the threat to the self that HIV constitutes. AIDS is associated with deviance and perversion and is represented as foreign, only affecting out-groups and originating from the 'other'. This 'othering' can be viewed as an example of Klein's concept of splitting, a defense against anxiety, where the good object (me) and bad object (HIV-positive people) are kept separate in mind (Joffe, 1999). According to Rohleder and Gibson (2006): "Representing AIDS as a disease that originates from and affects 'others', functions as a defense against the anxiety of being at risk of infection: thus AIDS is a disease that affects 'others' and not me" (p. 28). Another defense that is employed in attempts to defend against the anxiety evoked by HIV/AIDS is projection, or the process of attributing one's own threatening feelings and thoughts to an external other. Campbell, Foulis, Maimane and Sibiya (2005) state:

> People may cope by projecting their worst fears onto identifiable
> out-groups. This process of stigmatization…is thought to serve
> an 'identity-protective' function by producing feelings of
> comfort and security and a sense of personal invulnerability to
> threats and dangers that might otherwise appear overwhelming
> (p.2).

According to Joffe (1999) the stigmatization can be explained through the process of projection and the existence of a universal unconscious fear of collapse and chaos (Joffe, 1999). Using Jungian theory, Neumann explains this concept (1973):

> The ego, which is dependent on guidance by the Self, cuts itself
> off in opposition to the Self, which is the totality – Self and body

> – Self encompasses also the rejected lower aspect of the body
> and the world, and, by introjecting the negatively evaluated
> group conscience, bases itself on the super-ego repression. The
> split of the personality gives rise to aggressions which are either
> projected outward in a destructive, moralistic effort to destroy
> evil in others (scapegoat psychology) or else – when this is not
> entirely successful – lead to an intensification of the guilt
> feelings which continue to nourish the cultural process of taboo
> and self-defence (p. 133).

So, while individual defenses, such as splitting and projection, play an integral role in the creation and perpetuation of HIV/AIDS stigma, notions such as 'a universal unconscious fear of collapse and chaos' and a 'negatively evaluated group conscience' suggest that stigma is also something that occurs on a broader societal level. According to Campbell et al. (2005):

> Whereas the form and content of stigma will vary from one
> context to another, various forms of stigma are united by the way
> in which they serve to support systems of social inequality and
> social difference and to reinforce the interests of social actors
> seeking to legitimize their dominant status (p.2).

In other words, stigma can be seen to serve a 'system-justifying' function (Jost & Banaji, 1994). This is evident in that the psychological processes associated with 'othering' can be seen to serve wider social interests e.g. beliefs that women are the primary transmitters of HIV links them with ideas of diseased sexuality which serves to reinforce the general devaluation of women. According to Parker and Aggleton (2003) "stigma feeds upon, strengthens and reproduces existing inequalities of class, gender and sexuality" (p. 13).

On this broader level, South Africa's past and present social, economic and political climates can also be seen to play a role in perpetuating the stigmatization of HIV-positive

people, as these climates influence belief systems and attitudes. According to Posel (in Campbell et al., 2005) South Africa is currently engaged in the complex and vulnerable task of building a newly democratic and unified nation and that it is within this wider matrix of social instability, moral anxiety and political contestation that public discourses and silences around sexuality and HIV/AIDS are embedded.

> The widespread stigmatization of sex in South Africa and President Mbeki's well-publicized refusal to acknowledge the extent of the AIDS problem have been linked to the president's project of post-apartheid nation-building and to his conception of the type of citizen best equipped to carry forward his vision of an 'African Renaissance'. The president makes a strong distinction between South Africa's wretched past and a bright, new post-apartheid future. AIDS, and its association with promiscuous and diseased sexuality, threatens to blur this distinction (Campbell et al, 2005, p.3).

Thus it can be seen that defenses employed to defend against anxiety evoked by the possibility of HIV infection, such as splitting and projection, seem to perpetuate HIV/AIDS stigma and that this stigma is closely related to the wider social context and needs to be understood within it.

2.4. HIV/AIDS, DEATH AND DYING

2.4.1. Introduction

"Death is still a fearful, frightening happening, and the fear of death is a universal fear even if we think we have mastered it on many levels" (Kubler-Ross, 1970). According to Rando (1992) death threatens the human being as it represents the negation of all that she values in life, including, finally, her very self. McKay (1990) states that the reality of

death points to the absurdity of the whole human enterprise in that it seems doomed to end and to move into nothingness. However, McKay (1990) believes that there is good that can emerge from an awareness of death, in that through facing the threat of nothingness, a person is then able to live her remaining days with the authenticity of true self-understanding. Without confrontation of one's fears around death, life becomes filled with fear of living an incomplete and unfulfilled life. This notion is supported by an American study conducted by Goggin et al., (2001) in which they found that the awareness of a limited life span entailed by an HIV positive diagnosis can be a motivating factor and a "powerful force for healthy behaviour change" (p. 86).

The data from the study revealed that the vast majority of the participants had lost spouses, children, family members and/or friends to HIV/AIDS, making this a part of the reality of coping with HIV/AIDS. Sikkema, Kalichman, Hoffman, Koob, Kelly and Heckman (2000) conducted a study into the coping strategies used by HIV-positive individuals after experiencing an AIDS-related bereavement and found that "bereavement coping challenges can be especially difficult and pronounced for persons who are themselves HIV-positive" (p. 613.). Their study also found that grief was closely associated to avoidance coping strategies, including emotional suppression and recommended interventions for AIDS-related bereavement "that reduce stress and maladaptive ways of coping…in order to meet the secondary prevention needs of bereaved people living with HIV/AIDS" (Sikkema et al., 2000, p. 613). So, in addition to having to contend with the realities of their own HIV status, illness and mortality, many of the participants in this study have had to cope with the illness and death of loved ones. For many, the process of coping with their own status has blended with the process of mourning for loved ones. Hence, it is important that the concept of grief and the process of mourning are explored in this literature review.

Silverman (1999) explored grief as occurring within a relationship and Stroebe, Gergen, Gergen and Stroebe (1993) consider grief as a phenomenon that derives meaning from the socially constructed ideas that surround death and bereavement. More recent approaches to bereavement have broadened beyond exploring the individual response to

loss and have begun to explore grief within context. The 'context' of death can be described as the current societal and cultural beliefs that impact on our thinking and feeling about death. It is important insofar as it impacts upon the way humans cope with their own mortality and the mortality of their loved ones. According to Kubler-Ross (1970) due to advances in technology death in the Western world has become increasingly separated from human experience, hidden in ICUs and regarded as an abhorrent event. Jung (1933) even commented on modern society's attempts to hold onto youth, losing the wisdom of age and the meaning associated with nearing death.

Traditional African culture, on the other hand, holds that "life and death, secular and sacred, night and day, black and white, ugliness and beauty are not antagonistic polarities, but they are constant and continuing forces" (Jahn, 1990, p. xxi). According to Derr, Roussillon and Bournois (2004) African culture tends not to conceptualize and compartmentalize life, for example, into professional life, home life, life on Earth or afterlife, as is done in the West. Rather:

> Given that life is rooted in the distant past (with preceding generations) and that it branches out into an equally distant future (including both the living and the unborn), it is quite naturally lived in continuity. Since death is a perfectly natural step in this ceaseless process, Africans can weep for their dead without being terrified at the prospect of their own life's end (Derr, Roussillon & Bournois, 2004, p. 208)

While some of these traditional beliefs are evident today in African culture, the stigma around HIV/AIDS seems to influence this natural acceptance of death and complicate the process of mourning and preparing for death. A study conducted by Kilonzo and Hogan (1999) investigated the psychological significance of traditional African mourning practices within the context of the HIV/AIDS epidemic. The study found that untimely multiple losses through AIDS were increasingly forcing communities to forgo traditionally prescribed mourning practices and rituals. The study associated this

incomplete mourning and unresolved grief with increased psychiatric and psychological problems due to the inadequacy of these "abridged mourning processes" (Kilonzo & Hogan, 1999, p. 259). It is important that this is held in mind throughout the discussion of death and mourning that follows.

This section provides a combined review of literature around the process of grief and mourning for oneself that accompanies being given a terminal diagnosis and the process of grief and mourning for the loss of a loved one. This section also looks at normative versus pathological grieving according to current Western conceptualizations.

2.4.2. Theoretical conceptualisations of grief and mourning

There are many theoretical explanations for the process of grief and mourning. The first clinical descriptions of behaviours associated with grief classified the psychological and somatic manifestations as 'acute grief syndrome' (Noppe, 2000). Writing from an evolutionary perspective, Averill (1968) considered the fact that certain reactions to grief occur across cultures and considered this "syndrome-like behaviour... evidence of the universality of grief and maintained that its significance was for the continuation of the social order, the species itself" (Noppe, 2000, p. 521). However, other studies have challenged the idea of the grief experience being universal and have attempted to discern whether the behaviours and processes associated with grief and mourning are influenced by other factors such as culture, gender and personality (Noppe, 2000). These studies suggest that: "within the universal experience of loss are patterns or styles of grieving that are determined by a variety of factors, such as gender, cultural context, ages of the survivor and the deceased, and the mode of death" (Noppe, 2000, p. 533). It has also been suggested that a further mediator of the grief response may be the nature of the attachment that the bereaved experienced with the deceased (Noppe, 2000), however, this will be discussed in more detail later in this chapter.

Other studies have attempted to clarify whether grief happens in stages or if it would be better understood as tasks to be accomplished (Corr, 1992). Possibly the most well-known theorist on the stages of grieving is Kubler-Ross (1970), whose theory will be discussed in more detail later in this chapter. Other studies on grief and mourning have tried to determine whether the resolution of mourning is relinquishing the relationship to the deceased (Noppe, 2000).

Freud's (1917) account of mourning and melancholia is considered influential as it elucidated a number of concepts that are still regarded as relevant today. Freud (1917) considered grief to be a normal process that is different from depression, during which it is necessary for the ego to disengage from the lost 'other'. This process entails the libidinal energy invested into the attachment with this 'other' repeatedly reaching out and finding the object gone, until the libidinal energy can be disengaged from the attachment with the lost object and invested into other new relationships. According to Noppe (2000):

> In the classic psychoanalytic perspective, the lost 'object'…which one has either introjected (incorporated within the self) or identified with must be given up. Sometimes this inner representation of the dead one is intensified (hypercathexis) early in grieving but it is ultimately relinquished through a continual process of reality testing (p. 521).

However, the notion that relationships need to be severed for grief to be resolved has been challenged (Noppe, 2000) and the idea that successful resolution of grief necessarily entails an emotional disengagement from the deceased has been questioned (Stroebe, 1992; Klass, Silverman & Nickman, 1996). This question has come to be known as the 'broken bonds' versus 'continuity of bonds' debate (Noppe, 2000). Although Bowlby's (1980) theory on grieving was formerly considered to be a 'broken bonds' theory, further consideration has revealed that this may have been a misinterpretation of his theory (Fraley & Shaver, 1999). According to Noppe (2000): "Regardless of what Bowlby truly

believed, interpreting attachment theory from the continuity of bonds perspective opens up many possibilities for understanding grief" (p. 524).

Many links have been found between attachment theory and theories on mourning. "Because the complement to attachment is loss and grief, it is not surprising that the links between the two have also been acknowledged in theories of grief and mourning" (Noppe, 2000, p. 515). While attachment theory explores the initial establishment and incorporation of relationships as 'internal working models', theories of bereavement tend to explore the reworking of these internal working models after physical loss. The initial internal working models that are established seem to play an important role in the "process of grief as mourners respond to the change in their relationship" (Noppe, 2000, p. 516). According to Harvey and Miller (1998) internal working models form the basis of an individual's 'assumptive reality' regarding relationships. After a loss, the need to make sense of loss is significant and for this reason, an individual's internal working models for relationships may undergo profound reorganization (Harvey & Miller, 1998). Hence, the way that loss is managed is "dependent on the internal working model of the self and attachment figure that has been constructed during childhood" (Noppe, 2000, p. 519). According to Noppe (2000):

> It seems that looking at loss through death through the lens of the attachment perspective underscores the continuity of attachment relationships…It makes sense, from this perspective, that relationships are not severed by death. However, the crisis of loss does eventually necessitate a revision of the inner representations of the relationships that are responded to in different ways depending on the relationship history and cognitive strategies that are available to the bereaved (p. 534).

Thus, a complete emotional disengagement from the attachment to a deceased loved one may not be necessary for the resolution of grief. According to Stroebe (1992) the idea

that successful resolution of grief entails 'letting go' of the deceased may be a social construction of modernist Western culture, in which functionalism and independence are affirmed. In some cultures, the continuance of bonds through sustained grieving is admired and affirms the significance of the relationship. Hence, the appropriateness and validity of the universal application of the broken bonds approach to normative grieving may be questionable. According to Stroebe (1992) sensitivity to the culture of the bereaved and respect for a diversity of responses to death are important. According to Noppe (2000):

> …attachment theory and theories of bereavement can contribute to a postmodern analysis that looks not at broken bonds, but at the integrity of people as they deal with the dialectic of continuity and change in response to their relationships over the life course (p. 534).

2.4.3. 'Pathological' Grieving

Many studies on grief have attempted to differentiate between 'normal' grief and pathological grief (Rando, 1992). Grief is most often considered pathological when the response to a bereavement is extreme and disrupts social and occupational functioning, and when, in some cases, the grief develops into other psychopathology, for example, a major depression. Most theorists have settled on the term 'complicated' grief in order to differentiate between the extreme reactions and behaviours associated with loss and other forms of psychopathology.

A variety of subtypes of complicated grief have been identified, however, according to Rando (1992) in nearly all kinds of complicated grief, denial plays a role as the bereaved individual attempts to deny the loss and hold onto the lost person as before. According to Noppe (2000) the basis of pathological grief reactions is the failure to integrate the loss into current thinking and behaviour. Rando (1992) writes about absent grief, where the

grief reaction is inhibited or denied. Parkes (1991) writes about delayed grief, which is when the normal grief response does not occur for weeks or even years after a loss. Zizook and Lyons (1990) write about unresolved or chronic grief, which is when the grieving process is prolonged and incomplete. Noppe (2000) states that according to the broken bond hypothesis:

> …grieving should eventually result in the severance of the attachment relationship between the survivor and the deceased figure of attachment so that there can be concomitant reinvestment into other relationships. Thus, many theories of grief and mourning promote the notion that grief ends when there is 'resolution', 'recover', or 'reintegration', the terms themselves implying that this is a desired and healthy outcome (p. 522).

However, as discussed in the previous section, the broken bond hypothesis has been challenged and this needs to be taken into account when considering the notion of complicated versus normative grief. According to Silverman (1999) the idea that grief should come to an end and that this involves the 'letting go' of the deceased is derived from the medical model, where disease processes are thought of as internal. Treatment is hence aimed at the individual with little consideration of their social relationships or the context in which their loss has occurred. In some cases, the bereaved do not 'let go' of their deceased loved one but still manage to maintain a functionally 'sane' life (Silverman & Klass, 1996).

Hence, perhaps a new focus of what constitutes as pathological with regards to grieving needs to be explored. According to Noppe (2000): "Unfortunately, there are no commonly agreed upon definitions of what constitutes a pathological version or grief" (p. 522). In terms of cultural sensitivity, there exists the idea that the individual themselves will decide that their grief is not normal if they experience unbearable levels of distress. In this regard, it is important to explore emotional reactions towards loss.

According to Kubler-Ross (1970) the unconscious cannot distinguish between a wish and a deed. In other words, fantasy and reality merge in the realm of the unconscious. She explains this using an example of a child who buries his beloved dog and says "I will bury my doggy now and next spring when the flowers come up again, he will get up" (Kubler-Ross, 1970, p. 3). She likens this wish to ancient Egyptian and American Indian customs of supplying their dead with food and burying relatives with belongings. Kubler-Ross regards this inability of the unconscious to differentiate between fantasy and reality as important with regards to unresolved conflict in relationships preceding a death. Just as our wish may have been to resurrect our loved one after death, we may have at times of anger, wished our still living loved one dead.

> Just as we, in our unconscious minds cannot differentiate between the wish to kill somebody in anger and the act of killing, so the young child is unable to distinguish between fantasy and reality. The child who angrily wishes his mother to drop dead for not having gratified his needs will be traumatized greatly by her actual death – even if this event is not linked closely in time with his destructive wishes. He will always take part or all the blame for the loss of his mother…When we grow older and begin to realize that our own omnipotence is not really so great, that our strongest wishes are not powerful enough to make the impossible possible, the fear that we have contributed to the death of a loved one diminishes – and with it the guilt (Kubler-Ross, 1970, p. 3).

However, there is always the possibility that this guilt can be re-evoked by the death of a person with whom one had a deeply conflicted relationship. The guilt can then evoke a fear of punishment or retribution. Bowlby's (1980) theory on grief and mourning supports this idea. Bowlby (1980) explored complicated grief from an attachment perspective and found that individuals who exhibited pathological grief reactions tended to have experienced problems in their relationship histories and in their attachment to the deceased person before their bereavement. Kubler-Ross (1970) states:

A husband and wife may have been fighting for years, but when the partner dies, the survivor will cry and be overwhelmed with regret, fear, and anguish, and will fear his own death more, still believing in the law of talion- an eye for an eye, a tooth for a tooth – 'I am responsible for her death, I will have to die a pitiful death in retribution. Maybe this knowledge will help us to understand many of the customs and rituals that endured over the centuries and whose purpose is to diminish the anger of the gods or society, as the case may be, thus decreasing the anticipated punishment. I think of the ashes, the torn clothes, the veil, the Klage Weiber of the old days – they are all means of asking others to take pity on them, the mourners, and are expressions of sorrow, grief and shame. A person who grieves, beats his breast, tears his hair, or refuses to eat, is attempting self-punishment to avoid or reduce the anticipated external punishment for the blame he expects on the death of a loved one (p. 4).

This sense of death as punishment is then also important when understanding some dying people's belief that they are being punished for wrongs that they perceive they may have committed in their lives. Kubler-Ross (1970) writes that the predominant feelings at this time are grief, shame and guilt and that anger and rage are not far behind them. Anger is an integral part of any mourning process and a very human reaction to loss. Kubler-Ross (1970) states:

The five-year old who loses his mother is both blaming himself for her disappearance and expressing anger at her for having deserted him and for no longer gratifying his needs. The dead person then turns into something the child loves and wants very much, but also hates with equal intensity for this severe deprivation (p. 4).

The customs and beliefs of many cultures include symbolic representations of this anger, for example, the ancient Hebrew belief that dead bodies are unclean, the early American Indian custom of shooting arrows into the air to drive away evil spirits after death, or even maybe the tombstone to keep the 'evil spirits' deep in the ground (Kubler-Ross, 1970).

Thus, according to Kubler-Ross (1970) the emotions of shame, guilt, anger and rage can be considered typical of any response to loss, however, it is when these emotions present with increased intensity or duration due to unresolved conflict relating to the attachment the bereaved had with the deceased that the grief may be considered pathological. According to Bowlby (1980) dysfunctional attachment patterns in the relationship with the deceased can result in complicated grief due to the disruptions that then occur in the reorganization phase of grief. The necessary reworking of the internal representation in the bereaved person of the deceased becomes more challenging when the memories are inaccessible or conflicted. According to Silverman (1999) in these cases, the relationship with the deceased becomes 'encapsulated' and does not change despite the need for adjustment. These individuals may then also fail to engage in the cognitive restructuring of their view of self without the deceased that is considered necessary in the reorganization phase of mourning (Noppe, 2000).

With regard to the concepts of delayed or absent grief, Fraley and Shaver (1999) explain these reactions as a result of defensive structures developed in childhood. The notion of an insecure attachment style implies the development of a variety of defence mechanisms in interactions with others during infancy and childhood. According to Fraley and Shaver (1999) adults with these rigid defensive structures can become dismissing and may close off their feelings when faced with loss. Parkes' (1991) study on widows also found that the women who had anxious attachment styles tended to present with more mental health problems after the death of their husbands. According to Sable (1989) women with secure attachments to their parents suffered less distress, anxiety and depression after suffering a loss. Hence, according to attachment theory, the nature of an individual's

attachment style and the consequent type of attachment they had with a lost loved one will influence the manner in which they grieve.

2.4.4. Stages of grief

Bowlby (1969), who is best known as the founder of attachment theory, also created a theory of grief and mourning. Parallels were found between separation anxiety, which is the way that infants respond to separation and threat of loss of their attachment figures, and the grief of adulthood, which is how adults respond after the loss of a loved one. According to Bowlby (1980) there are four phases of normative mourning: a brief feeling of numbness, a longer period of yearning and searching for the deceased, then as the permanence of loss is acknowledged, a period of disorientation and despair, finally a period of reorganization as the individual adapts to life without the deceased. Parkes' (1972) theory of the stages of grieving also draws on the theory of attachment and emphasized that grief entails a period of adjustment and that this adjustment to life after the loss of a loved one entails major psychosocial transitions.

However, the stages of grief outlined by Kubler-Ross (1970) have possibly come to be the most widely known. While her initial theory covered the stages of mourning experienced by a patient diagnosed with a terminal illness, they have also come to be accepted as an appropriate description of the experience of the bereaved. This could be further elaborated as an acceptable and accurate description of any mourning for any kind of loss: be it divorce, the loss of a job, the death of a loved one, or the loss of hope for continued health and life. According to Kubler-Ross (1970) there are five identifiable stages of grieving. It is important to note that these stages do not necessarily occur in order or that once a person has moved to another stage this does not mean that they will not revisit a previous stage. The five stages are:

Denial and isolation

Initial denial is evident in the first stages in almost all individuals who are informed that they have a terminal or incurable illness. Partial denial is also used later from time to time. Kubler-Ross (1970) states:

> "Who was it who said, 'We cannot look into the sun all the time, we cannot face death all the time'? These patients can consider the possibility of their own death for a while but then have to put this consideration away in order to pursue life…the need for denial exists in every patient at times, at the very beginning of a serious illness more so than towards the end of life. Later on the need comes and goes…" (p. 35-37).

In most cases, denial is gradually replaced by partial acceptance. Maintained denial is rare (Kubler-Ross, 1970). Denial is useful and adaptive as it acts as a buffer after shock and it allows the individual time to mobilize other less extreme defenses. Kubler-Ross (1970) states:

> …the patient's first reaction may be a temporary state of shock from which he recuperates gradually. When his initial feeling of numbness begins to disappear and he can collect himself again, man's usual response is 'No, it cannot be me'. Since in our unconscious mind we are all immortal, it is almost inconceivable for us to acknowledge that we too have to face death. depending very much on how a patient is told, how much time he has to acknowledge the inevitable happening, and how he has been prepared throughout his life to cope with stressful situations, he will gradually drop his denial and use less radical defense mechanisms (p. 37).

Anger

Kubler-Ross (1970) writes about a number of what she calls 'fundamental facts' that are important when considering the human experience of dying. The first is that dying is almost always perceived as an attack from the outside of the self. Kubler-Ross (1970) states:

> When we look back in time and study former cultures and peoples, we are impressed that death has always been distasteful to man and will probably always be. To a psychiatrist this is very understandable and can perhaps best be explained in terms of our understanding of the unconscious parts of the self; to the unconscious mind, death is never possible in regard to ourselves. It is inconceivable for our unconscious to imagine an actual ending of our own life here on earth, and if this life of ours has to end, the ending is always attributed to a malicious intervention from the outside by someone else. In simple terms, in our unconscious mind we can only be killed; it is inconceivable to die of a natural cause or of old age. Therefore death in itself is associated with a bad act, a frightening happening, something that in itself calls for retribution and punishment (p. 3).

When denial ceases, it is replaced with anger, rage, envy and resentment. It is a difficult time for the dying person and for those caring for him or her, as the anger tends to be "displaced in all directions and projected onto the environment at times almost at random" (Kubler-Ross, 1970, p. 44). The dying person feels envy for those around who still have life and feels as if they will soon be forgotten. The patient's God is also often a target of their rage, feeling that they have been unfairly treated and/or abandoned. Kubler-Ross (1970) states: "The tragedy is perhaps that we do not think of the reasons for patients' anger and take it personally, when it has originally nothing or little to do with the people who become the target of the anger" (p. 46).

In many cases, the anger that these individuals feel is directly linked to their suffering and the perceived unfairness of their situations, however in some cases, it may be linked to previous unresolved anger and resentment from their lives (Kubler-Ross, 1970).

Bargaining

According to Kubler-Ross (1970):

> The third stage, the stage of bargaining, is less well-known but equally helpful to the patient, though only for brief periods of time. If we have been unable to face the sad facts in the first period and have been angry at people and at God in the second phase, maybe we can succeed in entering into some sort of an agreement which may postpone the inevitable happening: 'If God has decided to take us from this earth and he did not respond to my angry pleas, he may be more favourable if I ask nicely' (p. 72).

Bargaining usually involves a promise of 'good behaviour' in return for more time or less pain and is really an attempt to postpone. It also sets a self-imposed deadline and often includes an implicit promise that the individual will not ask for anything else if the first wish is granted. Bargains often include dedicating one's life to God if God grants him/her more time; or donating one's body to science if the doctors extend his/her life. However, very few people keep their promises in this regard and it is natural to want more. (Kubler-Ross, 1970).

According to Kubler-Ross (1970) it is important to understand that sometimes, underlying a bargain that is made is guilt, irrational fear or sometimes even the wish for punishment because of excessive guilt. This guilt then tends to be exacerbated by

"further bargaining and more unkept promises when the 'deadline' was past" (Kubler-Ross, 1970, p. 74).

Depression

According to Kubler-Ross (1970) when the terminally ill patient can no longer deny the gravity of their situation, the numbness, anger and rage are eventually replaced by a sense of great loss. This loss may take many forms according to the circumstances of the individual's life and their illness, for example, many may mourn the loss of their beauty, their physical strength, their job, their ability to care for their children etc.

Kubler-Ross (1970) writes about two distinct forms that this depression takes. The first is a reactive depression that involves past and recent losses that are normally accompanied by guilt and shame. With regards to this kind of depression Kubler-Ross (1970) states: "An understanding person will have no difficulty eliciting the cause of the depression and in alleviating some of the unrealistic guilt or shame which often accompanies the depression…we are always impressed how quickly the depression lifts when these vital issues are taken care of" (p. 76).

The second type of depression is a preparatory depression, where the patient experiences a preparatory grief in order to prepare him- or herself for separation from life and the world. "…this type of depression is necessary and beneficial if the patient is to die in a stage of acceptance" (p. 78). This depression does not involve past losses but takes into account impending losses. According to Kubler-Ross (1970):

> When the depression is a tool to prepare for the impending loss of all the love objects, in order to facilitate the state of acceptance, then encouragements and reassurances are not as meaningful. The patient should not be encouraged to look at the sunny side of things, as this would mean he should not contemplate his impending death.

It would be contraindicated to tell him not to be sad, since all of us are tremendously sad when we lose one beloved person. The patient is in the process of losing everything and everybody he loves. If he is allowed to express his sorrow he will find a final acceptance much easier…this second type of depression is usually a silent one in contrast to the first type (p. 77).

According to Kubler-Ross (1970) it is important to distinguish between these two types of depression as it can be extremely painful for patients when there is a discrepancy between their wishes and needs and those of the environment.

Acceptance

According to Kubler-Ross (1970) if given enough time, most terminally ill patients eventually reach a stage:

…during which he is neither depressed nor angry about his 'fate'. He will have been able to express his previous feelings, his envy for the living and the healthy, his anger towards those who do not have to face their end so soon. He will have mourned the loss of so many meaningful people and places and he will contemplate his coming end with a certain degree of quiet expectation (p. 99).

During this stage, the person is usually very weak and has an increased need for sleep. This need for sleep is not based on avoidance as in previous stages but rather "a time for 'the final rest before the long journey' as one patient phrased it" (Kubler-Ross, 1970, p. 100). It is not a happy time, but rather one that is devoid of feeling. According to Kubler-Ross (1970): "It is not a resigned and hopeless 'giving up', a sense of 'what's the use' or 'I just cannot fight it any longer'…" (p. 99). While these statements may mark

the beginning of the end of the struggle, they do not indicate that acceptance has been reached.

According to Kubler-Ross (1970): "We should be aware of the monumental task which is required to reach this stage of acceptance, leading towards a gradual separation (decathexis) where there is no longer a two-way communication" (p. 105). Kubler-Ross (1970) states that the achievement of this stage is often easier for older patients who feel they have lived their lives: "This is the older patient who feels at the end of his life, who has worked and suffered, raised his children and completed his tasks. He will have found meaning in his life and has a sense of contentment when he looks back at his years of work" (p. 105). However, for other patients, often the younger patients, more assistance is required in order for them to be able to progress through the stages and eventually reach a place that is free of fear and despair.

2.4.5. The role of hope

According to Compton (2005) people who have high levels of hope tend to experience more positive emotions. In addition to this, high levels of hope have also been associated with the anticipation of greater well-being in the future, higher levels of confidence, more success when dealing with stress, more flexibility in goal-planning and higher levels of social support (Snyder, Rand & Sigmon, 2002). According to Kubler-Ross (1970) hope is an extremely important emotion throughout the stages of grieving:

> The one thing that usually persists through all these stages is hope…in listening to our terminally ill patients we were always impressed that even the most accepting, the most realistic patients left the possibility open for some cure, for the discovery of a new drug or the 'last minute success in the research project'…it is this glimpse of hope which maintains them through the days, weeks, or months of suffering (p. 122 - 123).

This hope manifests in a variety of ways and for some it is the sense that there must be some meaning that will emerge from their experience. For others it is the wish that advances will suddenly be made in their treatment which will give them the strength to endure more tests. For some it is a rationalization for their suffering and for others, a temporary form of denial (Kubler-Ross, 1970). "No matter what we call it, we found that all our patients maintained a little bit of it and were nourished by it in especially difficult times" (Kubler-Ross, 1970, p. 123). Patients who stopped hoping usually died within 24 hours of having given it up.

2.5. HIV/AIDS, SHAME AND STIGMA

2.5.1. Introduction

The meaning of shame according to Wurmser (1981) is "to cover oneself" (p. 29). The concept of hiding is central to the meaning of shame and implies a sense of exposure, either physical or psychological (Pattison, 2000; Seu, 2006). The desire for concealment is clear when observing the physical expression of shame, which can include an averted gaze, a bowed head and a slumped body (Seu, 2006). According to Lewis (1987) shame is a painful state where the self is central to its experience - it is a state of self-devaluation which can result in feelings of inadequacy and hopelessness. Kaufman (1989) describes shame as the "affect of inferiority" (p. 17).

Brown (2006) employed a grounded theory methodology to research shame as a psycho-social-cultural construct. The study found shame to be "an intensely painful feeling or experience of believing we are flawed and therefore unworthy of acceptance and belonging" (Brown, 2006, p. 45). According to Brown (2006) shame is related to feelings of powerlessness with regards to meeting the expectations of others and isolation. Thus, shame can be seen to be a painful feeling of inadequacy in the face of the expectations of others, highlighting the role of 'others' in the experience of shame.

Many studies have explored the role of shame in certain psychopathologies, such as: depressive disorders (Ashby, Rice, & Martin, 2006; Epstein, 2001; Orth, Berking & Burkhardt, 2006; Scheff, 2001), trauma related disorders (Lansky, 2000) and stress responses (Trumbull, 2003). While theorists tend to agree on the painful subjective experience of shame, opinions vary regarding the basic nature of shame. Theories regarding the nature of shame include: shame being regarded as an innate, genetically transmitted mechanism of emotion (Gilbert, 1998; Schore, 1994; Tomkins, 1962, 1963); Lewis' (2003) view of shame as a self-conscious emotion requiring objective self-awareness; and anthropological and sociological perspectives that view shame as a socially defined phenomenon dependent on cultural contexts (Lindisfarne, 1998; Scheff, 2001; Turner & Stets, 2005).

This section will attempt to outline briefly how shame differs from guilt, shame as an intra-personal, inter-personal and social construct, and the role of shame in identity and depression. This section will also briefly discuss literature on shame in relation to gender and HIV/AIDS.

2.5.2. Shame as an intra- and interpersonal construct

Feeling shamed implies a relationship to another, which suggests that shame is inherently interpersonal in nature (Epstein, 2001). This means that in order to experience shame, an individual would have to compare their action to a standard either in themselves or in others. Shame is experienced when the individual fails to meet the standards, rules and goals set forth by the self (Lewis, 1992; Naso, 2007). Hence the distress and pain of shame is caused by the realization that an individual is inferior to an expected or desired state of existence that he/she imagines others to perceive him/her to be (Goldberg, 1991). The notion of shame being an interpersonal construct is evident in relation to HIV/AIDS, as according to Rohleder and Gibson (2006) an HIV-positive woman whom they interviewed reported that her "feelings of shame, fear, being damaged and dangerous

became more unbearable when she is sick and carries signs of her illness, like stigmata. When sick, she makes attempts to disguise her illness as being another disease…" (p. 37). The hiding of the illness and disguising it as another more socially acceptable illness implies that a large proportion of the shame associated with HIV infection is related to the anticipated negative reaction of others or society at large.

However, although shame is seen as developing in relation to another, the self begins to activate shame even when the original shame-provoking stimulus is no longer present (Banmen, 1988). Hence, shame can be experienced as being seen from the 'outside' or assessed, even when the assessment occurs internally (Lewis, 2003; Pattison, 2000; Trumbull, 2003). This has been hypothesized to be a result of the identification with images, ideas, and voices that the child internalises during his or her development. It is thought that these unconscious images then guide behaviour and contribute to the relationship with the self (Kaufman, 1989; Lewis, 1992; Miller, 1996). Hence, the internalisation of external interactions with significant others during psychological development causes children to experience shame as a result of the intrapsychic dialogues ensuing from internalised accusing others (Trumbull, 2003). Hence, the self that begins to activate shame in the absence of actual others, in the case of HIV-positive individuals cane be seen to be society's stigmatized view of HIV/AIDS that has been internalised by HIV-positive individuals.

Shame and guilt are regarded to be the most controlling regulators of emotion and behaviour (Pines, 1995). Hence, one of the ways that societies regulate human conduct is to teach children to control the expression of their emotions (Nathanson, 1992; Pines, 1995). The shaping of moral standards is achieved through parents and authority figures in society communicating their pleasures and displeasures through the use of shame as mediator (Trumbull, 2003). This use of shame as a means to control and exercise power in society is strongly linked to the stigma around HIV/AIDS (see section on Culture, Religion, HIV/AIDS and stigma above).

In addition to being conceptualised as an intrapsychic variable that is set early in life, other theorists suggest that the painful experience of shame can also be conceptualised as a socially constructed phenomenon (Leeming & Boyle, 2004). According to Leeming and Boyle (2004) the manner in which individuals understand themselves within their particular social and cultural milieu dictates the contexts of real or probable social interactions in which feelings of shame may arise. Greenberg, Pyszczynski and Solomon (in Compton, 2005) suggest that "…it is social and cultural standards of behaviour that provide us with both a context for comparisons and the actual standards we use to make judgments. The results determine our feelings of value and self-worth" (p. 55).

The experience of shame is strongly associated with HIV/AIDS due to the stigma surrounding the disease. According to Joffe (1999) the stigma associated with HIV/AIDS means that a person diagnosed with HIV/AIDS needs to manage the "deviant identity which is seen as offensive and repellent in the broader society" (p. 47) that they are forced to internalise. According to Rohleder and Gibson (2006) "A strong feeling of shame may manifest as a result of this identification" (p. 28). Individuals recently diagnosed as being HIV-positive often experience feelings of shame, fear and despair at being visibly contaminated (Squire, 1997).

Lewis (2003) describes shame as a self-conscious emotion that is unlike other primary emotions because it originates through self-reflection and requires objective self-awareness. In other words, shame implies an awareness of some part of the self which we consider to be inadequate. This moves us to a discussion of shame as an emotion.

2.5.3. Shame versus guilt

Shame and guilt are often used interchangeably and various theorists have attempted to distinguish two distinct affective experiences (Jacoby, 1994). However, most theorists seem to agree that shame is experienced when the entire self is devalued, by others and oneself, and the individual feels shame about *being* bad, whereas guilt is experienced

when the individual perceives having *done* something bad (Jacoby, 1994; Lewis, 1987; Pines, 1995). According to psychoanalytic theory, shame occurs when the self fails to live up to the standards set by an 'ideal self', hence the focus of negative evaluation is the self and shame implies failure or flaw (Wurmser, 1981). Guilt, on the other hand, implies transgression and the focus is on an action (Banmen, 1988). Guilt may be easier to bear because it applies to a discrete offence that may be reparable through some sort of action such as apology or atonement (Pattison, 2000; Wurmser, 1981).

Other differences between the experience of shame and guilt can be found in the types of 'self versus other' focused cognitive competencies that form part of the evolved social defence systems of individuals. These involve metacognition, symbolic self-other representations and theory of mind (Gilbert, 2003). According to Gilbert (2003), while the experience of shame can activate the fight or flight response in self-defence, resulting in feelings of anger or shame, guilt often requires different motives and competencies, such as the individual being sensitive to the needs of others and the motivation to care for others.

Gilbert, Pehl and Allan (1994) investigated the model of shame proposed by Helen Block Lewis (1987). This model relates shame to helplessness, anger at others, anger at self, feelings of inferiority and self-consciousness. Strong correlations were found for the relationship between these phenomena and in particular it was found that self-consciousness was related to shame, but not to guilt. Baldwin, Baldwin & Ewald (2006) attempted to ascertain whether shame and guilt were related to self-efficacy. A correlation between reduced self-efficacy and shame was found, but none were found between reduced self-efficacy and guilt.

2.5.4. The impact of early experiences on shame

Schore (1994) states that the orbitofrontal regions of the cerebral cortex control the sympathetic and parasympathetic functions of the autonomic nervous system, which are

involved in producing emotion. The formation of the activities of these autonomic functions during the first two years of a person's life results in the distinctive style of a person's emotional expression (Schore, 1994). During the early years of an individual's life, there are numerous interruptions to positive affects that can result in either fleeting or chronic experiences of shame. According to Nathanson (1996) although the initial triggers of shame may have been chance occurrences, the more incidences an individual assimilates the more triggers are learnt for shame (Nathanson, 1996).

Claesson and Sohlberg (2002) conducted a study which explored how memories of early significant interactions with the mother were related to shame. The study found that memories of an ignoring mother were more highly associated to shame than memories of a blaming and attacking mother. This suggests that although negative, a blaming and attacking mother may represent involvement and communication, while the lack of attunement and non-communication in an ignoring mother's behaviour may contribute to the pain of social isolation inherent in the experience of shame (Claesson & Sohlberg, 2002). According to Claesson, Birgegard and Sohlberg (2007) frequent experiences of shame may result in significant negative consequences to an individual's view of self and to their interpersonal relations, as shame can interrupt affective communication limiting empathy and intimacy. According to Pines (1995) individuals who have experienced numerous and repetitive shaming situations during early phases of development, such as, violent and/or negligent parenting, victimisation, or traumatic events of sexual abuse, may have a weakened ability to deal with the conflicts, struggles and losses in life (Pines, 1995).

2.5.5. Defenses against shame

Shame can be described as an overwhelming and inescapable sense that a personal flaw has been exposed to another. The fear of being shamed can be so powerful that individuals will often use a number of responses and behaviours to defend and distance themselves from the experience (Naso, 2007).

Shame defences are varied and include strategies such as impulsive action (such as binge eating, drinking, impulsive sexuality, suicidality) and preoccupation and blaming (Lansky, 1992). Blaming can include externalization where objects external to the self are seen as responsible for the perceived defect (Zaslav, 1998). This is due to the fact that once an individual becomes aware of shame they will either accept it and adapt their self-image or they will be obliged to defend against it by using highly scripted strategies such as attacking the other or attacking the self (Nathanson, 1996). Some individuals do not dare to expose themselves and resort to using distancing defences, such as counter-attacking the other with sarcasm and belittlement, projection and intellectualizing (Pines, 1995). Other strategies for defending against shame include withdrawal and avoidance (Nathanson, 1996), anger and rage (Anastasopoulos, 1997), and repression and barring the concept of shame from shared discourse (Mollon, 2005).

Studies with regard to defending against the shame of HIV in particular, have also been done (Joffe, 1999; Rohleder & Gibson, 2006). Withdrawal and isolation are common initial defences employed by recently diagnosed HIV-positive people (Meursing & Sibindi, in Rohleder & Gibson, 2006). Rohleder and Gibson (2006) found that the HIV-positive women in their study tended to resort to defences such as splitting and projection to protect themselves from the threat to self that a stigmatized identity can pose. In these cases, the women's own feelings of 'badness' and vulnerability were attributed to others, for example, "…the 'bad other' became those people who yet did not know their HIV status…the woman positions these people as the ones deserving of pity or derision…these women seem to use this discourse to assert their own situation [knowing their HIV status] as more admirable" (Rohleder & Gibson, 2006, p. 36).

A further way that splitting is used by HIV-positive people to defend against the shame of their HIV-positive status is by splitting the self into an unhealthy self in the past and a healthy self in the present (Rohleder & Gibson, 2006; Soskolne, Stein & Gibson, 2004). According to Rohleder and Gibson (2006) this form of splitting is an attempt to distance themselves from the threat of illness that HIV entails and from the physical ailments or

'stigmata' of the disease, locating them safely in the past. This form of splitting allows HIV-positive individuals to hold onto a healthy, 'good' self (Crawford, 1994).

2.5.6. Shame and identity

As previously discussed in the section on the impact of early experiences of shame, it is clear that frequent and intense experiences of shame during childhood can influence an individual's identity and self-image (Claesson et al., 2007). According to Lindisfarne (1998) the subjective experience, context and expression of shame differ for men and women. Most of the research has focused on the differences in the experience of shame around body image (Lutwak, 1998). According to Bessenoff and Snow (2006) women who have internalised the cultural ideals for weight as their personal ideal have been shown to have higher levels of bodily shame. This is significant in terms of the impact of HIV/AIDS on weight and body image.

Shame as an interpersonal construct and the impact of shame on interpersonal relationships has been discussed, as has shame as an intrapersonal construct. The internalization of early shaming experiences was shown to have a profound impact on the development of the self-concept and later 'proneness to shame' (Tangney, 1995). Shame can also be an entirely internal experience that divides an individual both from him- or herself and from others. This may contribute to the alienating or isolating effect of shame (Kaufman, 1989). According to Andrews and Hunter (1997) shame as an affect can be regarded as multidimensional; shame can be experienced in relation to one's view of the physical self, the characterological self and the behaviour of the self.

2.5.7. Shame and Depression

'Inappropriate guilt' is one of the criteria for major depressive disorder in the Diagnostic and Statistical Manual of Mental Disorders (APA, 2000), however, Orth et al. (2006)

found that shame but not guilt elicits rumination that may result in depression. The study proposed that shame involves the perceived negative view of self from others, which lowers self-esteem and elicits persistent rumination about the problematic situation and increases depressive thoughts. Tangney (1995) suggests that when guilt is fused with shame it becomes inappropriate or excessive. It is the shame component of the affect that triggers psychological symptoms. So, while guilt that may start with negative feelings and remorse about what an individual has *done*, if it then generalizes to a global feeling of self-contempt and disgust related to how that individual *is,* it may be far more difficult to perceive as changeable than an objective behaviour might (Tangney, 1995). The Psychodynamic Diagnostic Manual (PDM Task Force, 2006) suggests that the characteristic pathogenic belief about the self in Depressive Personality Disorders is that there is something essentially bad about the self and the central affects are shame, guilt and sadness.

2.6. CONCLUSION

This chapter provided an overview of the literature around HIV/AIDS and mental health and coping, taking into account the influences of gender and socio-economic status. It also briefly reviewed the literature around HIV/AIDS and social support. The impact of HIV on identity with regards to culture, religion and the stigma around HIV/AIDS was also considered. A brief theoretical discussion around the definition of self was included and Western versus African concepts of self were discussed. The literature around death and dying was also reviewed and a brief discussion of the literature around shame was also included.

CHAPTER THREE

DISCUSSION OF THEORY

…even the best attempts at explanation are only more or less successful translations into another metaphorical language…

C.G. Jung

3.1. INTRODUCTION

The aim of this research is to analyse and interpret African women's descriptions of their experience of coping with HIV/AIDS using an integration of traditional psychodynamic theory with a newer positive psychology approach, in order to provide a unique in-depth understanding of these African women's experience of living positively with HIV and dying of AIDS. While each of these theories, standing alone, could provide a valuable theoretical description of these women's experiences, each theory tends to have a focus, which allows for in-depth understanding of certain areas of human behaviour to the minimization or exclusion of others. While positive psychology's focus on the aspects of human behaviour that allow people to cope and thrive allows for a broad understanding of these phenomena, it tends to minimize the role of suffering and the various defences employed by people when suffering. This gap is filled by traditional psychodynamic theories, which focus on these defences and provide a variety of descriptions of suffering from intrapsychic and interpersonal perspectives. It is felt by the author that the gap created by traditional theories' focus on 'pathology' is filled by positive psychology. Jung's analytic theory provides a model for development in adulthood that entails the integration of opposites and which, according to the author, also allows for the integration of theories with opposing foci and a more integrated, holistic description of what it means to live positively with HIV/AIDS. However, in order to use these theories to provide an integrated description, an understanding of the theoretical approaches used in the study is required. This chapter aims to provide an overview of the three theoretical approaches to be used, namely, positive psychology; object relations theory and analytical psychology.

Due to the fact that positive psychology as an approach is fairly new, it is comprised of a large amount of exploratory research on a wide number of topics and does not seem to offer at this stage, any overarching theory of human development. Object relations theory, however, is comprised of a number of theories of human development, offered by various theorists, that focus on the influence of early experience in infancy and childhood on personality development. While the work of D.W. Winnicott will be the focus of this

section, important contributions by other theorists that are relevant to the study will also be mentioned. The last theory to be used in this study is that of analytical psychology, which is based predominantly on the work of one theorist, namely Carl Gustav Jung. His theory focused on ideas around the structure of the self and on adult development, as opposed to development in early infancy and childhood. A brief discussion of the difficulties associated with studying African culture from a Western perspective is also included at the end of this chapter, as is a brief critical discussion on the theories used and the areas in which these theories diverge and overlap.

3.2. POSITIVE PSYCHOLOGY

3.2.1. Introduction

Positive psychology is a fairly recent movement that encourages focus on the more positive aspects of human kind. According to Compton (2005) positive psychology is an approach that attempts "to understand the positive, the adaptive, the creative, and the emotionally fulfilling elements of human behaviour…positive psychology studies what people do right and how they manage to do it. This includes what they do for themselves, for their families, and for their communities" (p. 4). Other theorists describe positive psychology as a scientific approach that studies optimal human functioning and the factors that allow both individuals and communities to thrive (Sheldon, Frederickson, Rathunde, Csikszentmihalyi & Haidt, 2000). Positive psychology only really gained recognition as a movement in January 2000 after a special edition of the American Psychologist was devoted to positive psychology. In this edition, the American Psychological Association's president, Martin Seligman, announced the need for more focus in this area.

3.2.2. The Positive Psychology Movement

According to Maddux (2002) over the past few decades clinical psychology has come to follow the medical model with its focus on disease, diagnosis and treatment. According to Seligman, Parks and Steen (2004) this focus was due to the after-effects of World War II when psychology as a discipline had to be largely concerned with the classification, diagnosis and treatment of mental disorders:

> Many very distressed people were left in the wake of World War II, and the high incidence of mental disorders had become a pressing and immediate problem… researchers turned to the study of mental disorders because that was where the funding was. The biggest grants were coming from the newly founded National Institute of Mental Health, whose purpose was to support research on mental illness, not mental health…a wealth of excellent research resulted from this chain of events… [however] the downside of this accomplishment is that a 50-year focus on disease and pathology has taken its toll on society and on science (Seligman, Parks & Steen, 2004, p. 1379).

According to Gable and Haidt (2005) there are reasons other than World War II that may explain why psychology has focused on pathology rather than on the average person's strengths. The first of these is compassion.

> Those who are suffering should be helped before those who are already doing well. We certainly agree with this notion; however, we also think that an understanding of human strengths can actually help or prevent or lessen the damage of disease, stress and disorder…a better understanding of the environmental conditions and personal strengths that buffer against illness will actually equip

us to better help those who are suffering (Gable & Haidt, 2005, p. 105-106).

The second reason is that of evolution: "…our field's focus on the negative may well reside in our own nature…" (Gable & Haidt, 2005, p. 106). A review of the literature suggests that negative events tend to have more impact than positive events and that the human tendency is to more fully process information about negative events (Baumeister, Bratslavsky, Finkenauer & Vohs, 2001). According to Gable and Haidt (2005) this primacy of negative information may be explained from an evolutionary approach.

> It may be evolutionarily adaptive to recognize potential threats more readily than potential rewards. The former may have had immediate and irreversible consequences for survival and reproduction, whereas the latter's impact on survival and reproduction may have been more indirect and reversible (p. 106).

Hence, the last half-century's focus on the negative seems understandable in light of the historical underpinnings, but nevertheless, the time seemed right for a shift in focus. In order to attempt to correct this imbalance in the focus of psychology, Seligman and Csikszentmihalyi (2000) edited a special edition of the American Psychologist (January 2000) that was devoted to positive psychology and stated that psychology as a field had neglected what made life worth living and that research needed to be focused on this area. Since then a huge amount of research has been undertaken in order to balance psychology's focus from pathology to health (Gable & Haidt, 2005).

Gable and Haidt (2005) state, however, that research on positive psychology topics is not new and that the findings gained from these studies, according to Seligman and Csikszentmihalyi (2000) suggest that there is "…little empirical justification for our predominantly negative view of human nature and the human condition" (Gable & Haidt, 2005, p. 107). According to Seligman, Rashid & Parks (2006) goals like "individuation, self-realization, and peak experiences (Maslow, 1971), full functioning (Rogers, 1961),

maturity (Allport, 1961), and positive mental health (Jahoda, 1958)" (p. 775) have tended to be seen as luxuries that the rushed clinician cannot afford to address with patients. However, positive psychology emphasizes the importance of these human strengths and virtues in the prevention of mental illness. Seligman and Csikszentmihalyi (2000) state that "Prevention researchers have discovered that there are human strengths that act as buffers against mental illness: courage, future-mindedness, optimism, interpersonal skill, faith, work ethic, hope, honesty, perseverance, and the capacity for flow and insight, to name several" (p. 7). "Therefore, it is not surprising to us that what has come to be known as the positive psychology movement grew so rapidly from its beginnings" (Gable & Haidt, 2005, p. 107).

3.2.3. The scope of positive psychology

According to Seligman and Csikszentmihalyi (2000) positive psychology focuses on three main areas: positive subjective states, positive individual traits and positive institutions. Positive subjective states include constructive thoughts and positive emotions and their effects. Positive individual traits include character strengths and virtues, while positive institutions include healthy families, work environments and communities (Compton, 2005). Living the 'good life' is a concept that has been explored by positive psychologists and according to Compton (2005):

> …the good life has been seen as a combination of three elements: positive connections to others, positive individual traits, and life regulation qualities. Aspects of our behaviour that contribute to forging positive connections to others can include the ability to love, the presence of altruistic concerns, the ability to forgive, and the presence of spiritual connections to help create a sense of deeper meaning and purpose in life. Positive individual traits can include, among other elements, a sense of integrity, the ability to play and be creative, and the presence of virtues such as courage and humility.

Finally, life regulation qualities are those that allow us to regulate our day-to-day behaviour in such a way that we can accomplish our goals while helping to enrich the people and the institutions that we encounter along the way. These qualities include a sense of individuality or autonomy, a high degree of self-control, and the presence of wisdom as a guide to behaviour (p. 7).

It is important to note here that positive psychology emphasises social context and regards relationships with others and society as essential to the sense of a life well-lived. Positive psychology also attempts to recognise cultural differences in the definition of happiness or the good life. According to Compton (2005) "Positive psychology, as well as all of psychology, is beginning to explore cross-cultural comparisons that may enhance our understanding of how people throughout the world experience psychological well-being" (p. 9).

Compton (2005) also identified other themes and assumptions that underlie the basic tenets of the positive psychological approach. These include the assumptions that: people are adaptive; people desire positive social relationships; people can thrive and flourish; and that strengths and virtues are central to well-being. The notion that people are adaptive is well-known and positive psychology has linked this to the fact that people are social beings, hence the ability to live harmoniously in groups has been identified as a trait that would provide an evolutionary advantage to the species (Buss, in Compton, 2005). The idea that people can thrive is based on the move away from a focus on distress toward a focus on joy and flourishing in the face of change. According to Compton (2005):

> All too often, psychological research displays a blatant bias toward assuming that people are unwitting pawns to their biology, their childhood, or their unconscious. Positive psychology takes the position that in spite of the very real difficulties in life, we must acknowledge that most people do

quite well. Most people at least try to be good parent, to treat others with some degree of respect, to love those close to them, to find ways to contribute to society and the welfare of others, and to live their lives with integrity and honesty. These achievements should be celebrated rather than explained away as 'nothing but' biological urges or unconscious attempts to ward off anxiety and fear (p. 8).

The assumption that strengths and values are central to the concept of well-being is emphasised by positive psychologists, but again the importance of individuality and cultural considerations are taken into account. While research has investigated the possibility that certain values are found almost universally across cultures, it has also focused on values that contribute to an improved quality of life within certain communities (Compton, 2005). According to Smith (in Compton, 2005) psychology cannot decide which values are best, but rather, can comment on the consequences of holding certain values within certain cultures.

3.2.4. Positive coping

Research on coping within the positive psychology approach has focused on establishing why certain people cope better with stressful life situations than others (Compton, 2005). Snyder and Dinoff (1999) define coping as a response that is elicited for the purpose of decreasing the physical, emotional and psychological impact of stressful occurrences. Carver, Scheier and Weintraub (1989) state that coping should be viewed as a dynamic process that changes in nature in different stages of a stressful transaction. This suggests that the development of a coping style would be counterproductive, because it locks an individual into one style of responding rather than allowing him/her the freedom and flexibility to change responses with changing circumstances.

Folkman and Lazarus (1988) state that coping styles can be grouped into three distinct styles: problem-focused coping, emotion-focused coping and avoidance. Problem-focused coping seems to predominate when people feel that something constructive can be done to change the situation that caused the stress. Emotion-focused coping is used more when people feel that the stressor they face must just be endured and they attempt to change the negative emotions they feel about the situation. Avoidance occurs when people try to avoid the problem and the associated emotion altogether. Problem-focused coping involves several distinct activities i.e. planning, taking direct action, seeking assistance, screening out other activities and sometimes delaying or waiting before action (Carver et al, 1989). According to Folkman and Lazarus (1988) problem-focused coping can be divided into two methods: those aimed at changing the situation and those aimed at changing the self. Problem-focused coping aimed at changing the self often involves cognitive reappraisals, where one might look at one's thoughts and beliefs about a situation.

According to Carver at al., (1989) emotion-focused coping is a diverse concept. It is a coping tendency aimed at managing distress emotions rather than at dealing with the stressor per se and it can involve denial, positive reinterpretation of events and also seeking out social support. Emotion-focused coping is "directed at regulating emotional responses to problems" (Folkman & Lazarus, 1984, p. 150). Folkman and Lazarus (1988) identified two types of emotion-focused coping, namely, cognitive and behavioural. Cognitive emotion-focused coping involves defensive re-appraisals i.e. reinterpretations of the situation that draw attention away from the more painful aspects of the situation e.g. selective attention and using positive thoughts to block negative thoughts. Behavioural emotion-focused coping is when people do something to regulate their emotions like venting, meditation and exercise. Although some emotion-focused coping styles can be adaptive in some circumstances, there are a number of emotion-focused coping techniques that are maladaptive. According to Carver et al. (1989) one emotion-focused coping technique that can be problematic is 'focusing on and venting of emotions', which is the tendency to focus on whatever distress or upset one is experiencing and to ventilate those feelings. They state that although such a response

may sometimes be functional, such as mourning the loss of a loved one, focusing on negative emotions (particularly for long periods) can impede adjustment, since the salience of the distress may exacerbate the distress.

There are two other coping tendencies that Carver et al. (1989) feel may be maladaptive in many circumstances. The first is 'behavioural disengagement', which is when one reduces one's efforts to deal with a stressor, to the point of giving up the attempt to attain goals with which the stressor is interfering. Behavioural disengagement is associated with phenomena such as helplessness and is most likely to occur when people expect poor coping outcomes. The second tendency Carver et al. (1989) identified is that of 'mental disengagement'. Mental disengagement occurs through a variety of activities, which are used to distract a person from thinking about the behavioural dimensions or goals with which the stressor is interfering. In other words, alternative activities are used to take one's mind off a problem.

In many situations, people tend to use a combination of emotion- and problem-focused coping strategies and it is important to note that certain strategies seem to be more effective in certain stressful situations (Compton, 2005). According to Stanton, Parsa and Austenfeld (2002) emotion-focused coping can be beneficial as it helps manage overwhelming emotion in order to enable the person to engage with the stressor. For example, denial, which is an emotion-focused coping style can be beneficial in the early stages of an illness.

Gender and cultural differences have also been noted in the types of coping people use. Women are more likely to seek social support than men, in the same way that certain cultures value seeking support more than trying to work through the problem internally (Compton, 2005).

The notion of positive coping is one that incorporates the idea that coping with stressful situations allows for learning and the building up of resources which can buffer against future stressor. Folkman and Lazarus' (1988) study on coping suggested that when

cognitive appraisals of negative life events are put into perspective through comparing the event with the perceived abilities of the individual to cope with these challenges, the individual's distress can be mediated. In other words, positive coping is the process through which adaptations that are necessary to cope are made, and through these people become stronger and their general quality of life increases. This is known as thriving, a term which has come to denote the improved physiological and psychological functioning after a person has successfully adapted to a stressor (Epel, McEwan & Ickovics, 1998).

The notion that negative emotions play a vital role in the survival of our species in that they prompt rapid responses to threats from the environment (Compton, 2005) is well-known, however, more recent research has suggested that positive emotions can also play a role in prompting action. According to Fredrickson's (1998) 'broaden-and-build' model positive emotions provide non-specific action tendencies that can lead to adaptive behaviour, such as, participating, exploring, helping or taking up challenges. This, in turn, can then lead to thought-action tendencies, which are based on the assumption that when more engaged with the world, one tends to learn more about their environment, others and themselves. Negative emotion tends to lead to a narrowing of thought, options and behaviour, as threat situations tend to require decisive thought and action. However, positive emotions tend to allow for creativity and the broadening of options (Compton, 2005). Fredrickson's (1998) model suggests that the broadening of awareness that positive emotions encourage, allows for learning and the building of future emotional and intellectual resources.

3.2.5. Emotional Intelligence (EQ) and the genetics of happiness

According to Compton (2005) emotions can be useful and "the ability to use emotions wisely might be considered a type of intelligence" (p. 27). According to Mayer, Caruso and Salovey (2000):

Emotional intelligence refers to an ability to recognise the meanings of emotions and their relationships, and to reason and problem-solve on the basis of them. Emotional intelligence is involved in the capacity to perceive emotions, assimilate emotion-related feelings, understand the information of those emotions, and manage them (p. 267).

Emotional intelligence is also associated with self-insight or the ability to understand one's own emotional life; good social skills, which include empathy and insight into the emotional life of others; and self-control or the ability to regulate one's own feelings and impulses towards the achievement of goals (Mayer, Caruso & Salovey, 2000). The levels of emotional intelligence that a person possesses have been found to have positive correlations with verbal IQ scores, levels of empathy, life satisfaction and levels of perceived parental warmth during childhood (Mayer, Caruso & Salovey, 2000). Averill (2002) proposed that people who are able to use their emotions in creative ways are able to create more meaning and connectedness in their lives.

Biologically based studies have found genetic tendencies with regards to emotional responses. Lykken and Tellegen (in Compton, 2005) found that up to 80 percent of the long-term stability of well-being is genetically based.

> In other words, they suggest that our families may be important to our eventual emotional lives as adults but not because of what we learn from our families, as Freud, Skinner, and others have suggested. Rather, families are important because they provide us with genetic material that largely determines our base emotional responsiveness to the world. Therefore they [Tellegen, Lykken, Bouchard, Wilcox & Rich] concluded that genetic make-up was far more important to the long-term quality of our emotional lives than is learned behaviour or the quality of our childhood environments (Compton, 2005, p. 29).

Hence, Lykken and Tellegen (in Compton, 2005) proposed the idea of a 'happiness set point', which is the genetically inherited average level of happiness to which they return after temporary highs and lows. This concept can be linked to the concept of temperament in babies (Kagen & Snidman, 1991; Winnicott, 1965). However, this argument for the role of genetics i.e. nature, in determining our experience is, as always, subject to criticism and the balancing argument of nurture. According to Compton (2005) there are a number of other factors that have also been shown to have a strong influence on a person's level of happiness and well-being, such as: the environment in which the person grew up, level of education and cultural factors.

3.2.6. Positive illusions versus self-awareness and realistic perceptions

According to Compton (2005) "Some intriguing and provocative contemporary research suggests that happiness as well as self-esteem, is often not related to an accurate perception of reality" (p. 56). Taylor and Brown (1988) found that overly optimistic and exaggerated evaluations and beliefs about the self, the future and perceptions of control were all positively correlated with mental health. Taylor, Kemeny, Reed, Bower and Gruenwald (2000) found that these positive illusions were associated with more effective coping with adversity and positive physical health outcomes.

The concept that people who hold enhanced, but inaccurate perceptions of themselves tend to be happier, is controversial and much debate has ensued. A number of researchers have argued that deliberate attempts to not see the world accurately should not be "recommended as a universal strategy for increased well-being" (Compton, 2005, p. 57). Goleman (in Compton, 2005), in particular, stated strongly that positive illusions and self-deception strategies could have broader societal implications: "…the use of denial, excuse-making, and succumbing to illusions of invulnerability can result in collective avoidance of problems such as environmental pollution, cultural genocide and other very real dangers that threaten humanity" (p. 57). Campbell, Reeder, Sedikides & Elliot (2000) also found that too much positive illusion regarding self-evaluations, as is

found in narcissists, is related to more negative evaluations from others. Beer and Robbins (2000) found that while positive illusions tend to work in the short-term for immediate threats to self-esteem, they were less effective over the long-term. It has been suggested that perhaps the answer lies in between absolute accuracy and absolute illusion. Positive illusions are helpful at certain times and in certain situations only (Compton, 2005). Baumeister (in Compton, 2005) "suggested that there may be an "optimal margin for illusions". That is, we can afford to lose some objectivity if it means gaining a bit more optimism about a future that we cannot predict anyway" (p. 57).

The corollary to this argument is that it is in fact higher levels of mental health that allow us to see ourselves accurately. Mental health by definition assumes a fairly accurate perception of reality, with many thought disorders being diagnosed due to the inability to accurately perceive reality (Kaplan & Saddock, 1998). Aspinwall and Brunhart (2000) found that happier people were more able to constructively work with negative feedback and had more motivation to solve the problems.

3.2.7. The role of control in well-being

One of the predictors of a sense of subjective well-being and satisfaction with life is a sense of perceived control (Compton, 2005). Related to Mayer, Caruso & Salovey's (2000) concept of emotional regulation, which refers to the ability to control and manage one's emotions, perceived control refers to a belief that one has some measure of control over the events that occur in life that are personally important (Compton, 2005). According to Ryan and Deci (2000) perceived control could even be considered to be an innate need. Rotter (in Compton, 2005) developed the idea of an internal versus an external locus of control, which describes the respective tendency to either attribute outcomes to "self-directed efforts rather than to external factor or chance" (Compton, 2005, p. 49). In general, the literature around locus of control suggests that having an internal locus of control is associated with a number of positive outcomes (Lefcourt, 2001). This finding can be related to the findings of studies on personal control

(Peterson, in Compton, 2005), which suggest that personal control is the belief that a person can make choices, cope with the results of these choices, and then learn from the outcomes of the choices in order to "maximise good outcomes and /or minimise bad outcomes" (Peterson, in Compton, 2005, p. 49).   The learning from the outcomes of choices is often linked to the process of finding meaning in experience (Compton, 2005).

What appears to be an exception to the notion that an internal locus of control is more beneficial is people who are religious and hold the belief that God holds all the control over their lives.   While this seems to be an example of an external locus of control leading to greater well-being, a belief in a greater power has now been found to be rather a form of "secondary control" (Rothbaum, Weisz & Snyder, in Compton, 2005).   According to Compton (2005):

> With secondary control, people can gain a sense of control by associating themselves with a person, philosophy, or system that they view as more powerful than themselves.   Therefore, in a somewhat paradoxical way, it is also possible to feel in control by consciously and deliberately giving up control to a more powerful force, such as God.   In other words, one can gain a sense of control by knowing that it was a conscious choice to relinquish control (p. 49).

Overall, Taylor et al. (2000) have found that experiencing a sense of personal control and having optimistic beliefs can function as protective factors for psychological and physical health.

3.2.8. The role of autonomy in well-being

Autonomy as a concept refers to the ability to make independent decisions about areas which the individual deems to be important (Ryan & Deci, 2000). It has been related to a sense of mastery or competence and having intrinsic as opposed to extrinsic motivation.

Intrinsic motivation "is operating when we are compelled to engage in some activity for its own sake, regardless of any external reward" (Compton, 2005, p. 34), whereas extrinsic motivation is "when we act to obtain some external reward, be it status, praise, money, or other incentive that comes from outside ourselves" (Compton, 2005, p. 34). According to Ryan and Deci (2000) people who are intrinsically motivated tend to perform better, show more persistence and creativity, and experience higher levels of well-being. Ryan and Deci (2000) also developed self-determination theory which suggest that a core group of innate needs are the basis for self-motivation and personality integration. These needs are the need for competence, the need for relatedness, and the need for autonomy. They postulate that intrinsic motivation develops from the desire to fill these three needs. According to Ryan and Deci (2000) these three needs "appear to be essential for facilitating optimal functioning of the natural propensities for growth and integration, as well as for constructive social development and personal well-being" (p. 68). Knee and Zuckerman (1996) found that people who are more autonomous and who did not feel pressure to conform were less likely to use defensive coping strategies.

3.2.9. The importance of goals and future-orientation

Being future-oriented or having goals for the future that are realistic and achievable has been linked to higher levels of well-being and life satisfaction. This may be due to the fact that the pursuing and achievement of goals that are meaningful to a person provide a sense of meaning and purpose in life (Compton, 2005). Goals can be defined as the dreams we hope to accomplish in the future (Compton, 2005). Goals that are freely chosen, realistic, valued personally and based on intrinsic motivation tend to bring more happiness and satisfaction than goals that are imposed by others or not valued as highly (Ryan & Deci, 2000).

While Kasser and Ryan (1993) found that goals that were linked to positive relationships and helping others; and that facilitated affiliation, self-acceptance and community involvement tended to enhance a subjective sense of well-being, while Cantor and

Sanderson (1999) found that goals that were self-centred tended to lower well-being. Goals valued by one's culture also tended to influence well-being (Cantor & Sanderson, 1999). Cultural differences have been found between the incidence of individually oriented achievement versus socially oriented achievement (Yang, in Compton, 2005). In Western culture individually oriented achievements and socially oriented achievements tend to be separate and both can be valued, while in certain other cultures there tends to be an emphasis on socially oriented achievement (Doi, in Compton, 2005).

A distinction has also been made between approach goals and avoidance goals. While approach goals motivate us to move toward something, avoidance goals motivate us to avoid dangers or difficulties (Compton, 2005). Interesting cultural studies have been done in this area and Diener, Oshi and Lucas (in Compton, 2005) found that in cultures that are more socially oriented, avoidance goals tend to be more common, as people tend to fear failure more as failure is seen to also reflect on their families.

Other concepts associated with having a future outlook are those of optimism and hope. Optimism can be defined as the tendency to look at the future with hope and positive expectations (Compton, 2005) and has been associated with higher levels of happiness and life satisfaction (Diener et al, in Compton, 2005). Optimism regarding the way that one perceives the status of one's physical health has also been linked to experiencing fewer health problems (Scheier & Carver, 1992).

3.2.10. Participation in life and social support

Gay (in Compton, 2005) challenged the idea that adult psychological distress is the result of the repression of negative childhood experiences and argued that adult distress in the form of anxiety, depression and worry is rather the result of the inability to recall joy, which leads to a withdrawal from active participation in life.

Cantor and Sanderson (1999) also suggested that one of the reasons that the pursuit of goals contributes to a sense of well-being is because it implies a sense of active participation in life. Involvement in an active life has been shown to increase one's sense of well-being, with the emphasis being on involvement and not necessarily on the activity chosen. Participation in life could also take the form of involvement in relationships, especially those that are mutually fulfilling. These relationships fill innate needs (Ryan & Deci, 2000) and could form the basis of the findings of the studies done on the positive effects of social support. Compton (2005) provides a definition of social support and states that it "can include emotional support such as caring and empathy, getting positive feedback about our behaviour, receiving helpful information, the willingness of others to give us their time or other tangible forms of assistance" (p. 112). One of the strongest predictors of well-being is the presence of positive relationships in a person's life (Myers, 2000). The need for social interaction between human beings has been shown and cross-culturally, it has been shown that satisfaction with family and friends is linked to higher levels of subjective well-being (Diener et al, in Compton, 2005). According to Compton (2005) there are generally two areas of study associated with positive relationships, namely, social support and emotional intimacy. According to Compton (2005):

> Numerous studies…have documented the positive impact that good social support can have on well-being. The perception that one is embedded in supportive social relationships has been related to higher self-esteem, successful coping, better health and fewer psychological problems…Interestingly, one study found that when people sought out social support there were enhanced effects on subjective well-being for positive self-esteem, optimism and perceived control…That is, the impact of the other predictors of subjective well-being was increased if people also had good social support. In a sense, good social support helped to create a rising tide that increased the effects of all the other predictors (p. 52).

Whereas research has shown the positive effects of good social support, it has shown even greater effects on levels of happiness and well-being when these relationships are intimate. According to Cummins (1996) intimate relationships with one's spouse, family and close friends are the strongest predictor of a high level of life satisfaction. Committed relationships have also been found to be a source of personal growth, in that the difficulties inevitably experienced in any relationship can be harnessed as motivation for self-exploration and gaining a deeper understanding of the self and one's partner. According to Tashiro, Frazier, Humbert and Smith (2001) difficulties in a relationship can create the need for partners to explore their own expectations and needs and the impact of their unconscious issues on the relationship. If successful in coping with the difficulties, both partners increase their development and the maturity of their relationship.

Another one of the predictors of a sense of subjective well-being and satisfaction with life is being extroverted, which implies a person "who is interested in things outside him- or herself, such as physical and social environments, and is oriented to the world of experiences external to self" (Compton, 2005, p. 50). While extroversion has been found to be one of the most significant predictors of well-being (Diener et al, in Compton, 2005) and been shown to be predictive of levels of happiness 30 years after the initial testing (Costa & McCrae, in Compton, 2005), the reasons for this are varied. While some researchers attribute extroversion's link to greater well-being as being due to spending more time with people and thereby gaining more opportunities for positive feedback, other researchers have shown that introverts do not necessarily spend less time with other people (Compton, 2005).

More recent research is suggesting, rather, that the reason extroverts report higher levels of well-being is that they are born with a greater sensitivity to positive rewards (Rusting & Larsen, in Compton, 2005) and have stronger reactions to pleasant events (Larsen & Ketelaar, in Compton, 2005). According to Lucas, Diener, Grob, Suh & Shao (2000) extroverts are more predisposed to experience positive emotions and this suggests that

more experiences are encoded into memory with links to positive emotion and are recalled as such.

3.2.11. The role of comparison in well-being

According to Compton (2005) our levels of self-esteem are closely tied to the judgments we make about ourselves. There are two main ways that comparisons are made. The first is by comparing one's actions to an internal standard that dictates the way one should be. Moretti and Higgins (1990) wrote about the ideal self versus the actual self and found that the smaller the discrepancy between the two, the higher one's self-evaluations tend to be and the greater one's sense of well-being. The second method of comparison is that of social comparison, in which one compares oneself to others. According to Compton (2005) there are three types of social comparison: lateral comparison, which is when one compares oneself to other who are similar; upward comparison, which is when one compares oneself to those who are deemed better than oneself on certain dimensions; and lastly, downward comparisons, which is when one compares oneself to people who one views as being less fortunate than oneself. According to Lyubomirsky and Ross (in Compton, 2005) studies show that people who tend to use downward comparisons more often tend to be happier. Compton (2005) warns though that if this process is taken too far, and people constantly see themselves as 'better than' others, it may turn into arrogance and narcissism.

3.2.12. Culture and positive psychology

According to Wierzbicka (in Compton, 2005) most cultures around the world have some concept of the generic notion of happiness as a appositive emotional state, however, according to Compton (2005) "Although all cultures have some conceptualization for the emotion of happiness, there are also substantial differences in how this general feeling is understood expressed and experienced" (p. 234). However, according to Berger and

Luckman (in Compton, 2005) the influence that culture has on thoughts about self, others and reality and how this influences subjective well-being is one of the least explored areas.

Studies that have been done have shown that high self-esteem is more strongly correlated to a high life satisfaction in individualistic cultures than in collective cultures (Diener & Diener, 1996). Self-consistency, which is the ability to remain fairly autonomous regardless of the situation within which one finds oneself, was found to be more highly regarded in individualistic cultures and negatively correlated with likeability in collective cultures (Suh, 1999). While the degree to which one experiences more positive than negative emotions during the day was important to people from individualistic cultures, it was not the same for people from collective cultures. According to Diener, Oshi & Lucas (in Compton, 2005) the amount of satisfaction one experienced with regards to self, freedom and recreation were correlated with overall life satisfaction in individualistic cultures, the correlation was weaker in collective cultures. In general, according to Compton (2005):

> Self-reports of high subjective well-being from people in individualistic countries tend to be based on awareness of one's emotional state, experiencing many positive emotions, success at achieving goals relevant to the self, inferring internal causality for positive outcomes, and pursuing immediate hedonic goals for fun, enjoyment or self-enhancement. In contrast, self-reports of high subjective well-being from people in collectivistic countries tend to be based on an awareness of and alignment with social norms, success at achieving goals that make others happy, and sacrifice of positive emotions in order to engage in activities that are related to future goals (p. 239).

3.2.13. Religion and well-being

In subjective well-being studies the concept religiosity has often been used to represent the experience of meaning and purpose in life (Myers, 2000), however, this has been found to be inaccurate as the experience of meaning and purpose in life does not necessarily need to be of a religious nature (Emmons, in Compton, 2005). Instead religion or being religious as a predictor of well-being needs to be considered on its own.

Firstly, it is important to distinguish between spirituality and religion. While spirituality tends refers to "the human tendency to search for meaning in life through self-transcendence or the need to relate to something greater than the individual self…spirituality does not depend on an institutional context" (Compton, 2005, p. 196), religion refers to "a spiritual search that is connected to formal religious institutions" (Compton, 2005, p. 196).

According to Compton (2005) there are a variety of studies that suggest that higher levels of religious faith, regular attendance at religious services and regarding religion as important in life correlate with higher levels of well-being. This could be due to a number of reasons, such as: religion providing a sense of meaning and purpose in life; greater levels of social support from the religious community; increased self-esteem through self-verification (a process through which a person's values are validated through sharing them with like-minded people); and the decreasing of existential anxiety and the fear of death through religious teachings about an afterlife. Studies have also linked regular engagement in religious activities with better physical and mental health, due to lower rates of delinquency, lower rates of alcoholism and drug abuse and lower rates of other social problems (Donahue & Benson, 1995). Argyle (1999) found that the strongest correlations were found between religiosity and well-being in certain groups, namely women as opposed to men, African-Americans as opposed to Caucasian Americans, and amongst the elderly. The strong relationship found in the elderly may be due to the fact that at that life stage their needs are such that they require religion more in their preparations for death. With specific reference to health, participation in religion

has been linked to living longer, quicker recovery from surgery or illness, having fewer illness and lower incidences of cancer and heart disease (George, Larsen, Koenig & McCullough, in Compton, 2005). However, when religious coping styles are over-relied upon they can have detrimental effects on health, for example, when faith healing is relied upon and other medical services are neglected (Asser & Swan, in Compton, 2005). This can also be seen when people begin to rely on faith to the point of neglecting to take active participation in their own health and well-being, for example, not exercising (Klonoff & Landrine, in Compton, 2005). Pargament, Smith, Koenig & Perez (in Compton, 2005) found that the most beneficial form of religious coping was when people saw themselves as working together with God to solve problems, as opposed to seeing the solution as lying with God alone.

Pargament, Smith, Koenig & Perez (in Compton, 2005) divided religious coping into two types: positive and negative. Negative religious coping is when people experience negative emotions, such as guilt or fear of retribution from God and punish themselves for wrongdoing to make amends to God. This form of coping is not linked to feelings of well-being. According to Pargament, McCarthy, Shah, Ano, Tarakeshwar, Wachholtz, Sirrine, Vasconcelles, Murray-Swank, Locher and Duggan (2004) "empirical studies suggest that religion and spirituality can be both resources for people with HIV and sources of pain and struggles" (p. 1201). Religious coping has also been associated with the need for meaning in life. Meaning in life is a concept that has long been associated with positive coping or thriving (Compton, 2005). Due to its abstract nature, meaning has been difficult to define, however two categories have been identified. Yalom (1995) identified 'cosmic meaning', referring to a design or sense of order in the universe. Park & Folkman (in Compton, 2005) identified 'global meaning', referring to the sense that human life fits into an overall coherent pattern.

Baumeister (in Compton, 2005) suggested four reasons why a sense of meaning in life is important. These include: a purpose in life, a sense of efficacy, legitimization or justification of actions, and a sense of self-worth. Meaning in life and religiosity have both been linked to generativity, which is one of Erikson's (1980) life stages in which

giving back to family and community become important. Yalom (1995) also wrote about how service to others can assist in creating a sense of personal meaning. By helping other people an individual gains a sense of adding to the greater welfare and 'making a difference'. This sense of making a difference to the world is associated with a sense of leaving a mark to be remembered by after death. However, according to Compton (2005), religion has also been negatively associated with helping others, when the 'other' is seen to hold different beliefs and values.

3.2.14. Positive coping and health

According to Compton (2005) for the past century physical health has been defined as the lack of illness or disease. In other words, physical health was defined as the absence of some other state, which is like defining psychological health as the absence of mental illness. With regards to scientific research criteria, "defining a phenomenon by what it is not fails to set any specific criteria for the object under scrutiny" (Compton, 2005, p. 108). However, according to Compton (2005):

> Recently, researchers have begun to focus on more expanded specifications of physical health and well-being. The World Health Organization (WHO), however, was years ahead of most scientists on this point. In 1948, their official position on health was, "Health is a state of complete physical, mental, and social well-being, and not merely absence of disease and infirmity". WHO has recognized for almost sixty years that while being disease free is a worthy goal, there is also a state of enhanced vitality that would help define a more encompassing sense of well-being (p. 109)

3.2.14.1. Salutogenesis, fortigenesis and hardiness

This movement toward a more integrative and positive approach to human health, in which it is acknowledged that health consists of many areas of a person's functioning, opened the door for exciting new fields of research (Compton, 2005). People began to explore health and what factors constitute and promote wellness. According to Geyer (1997):

> Over the last decade the focus has changed somewhat. In addition to further searches for potential pathogenic factors, a lot of interest has been devoted to conditions that might protect individuals from falling ill after having encountered stressful circumstances. The social support literature can be subsumed under this category…A very influential contribution to this line of research came from Aaron Antonovsky and his idea of 'salutogenesis', which is strongly connected with 'sense of coherence' (SOC)…[which] is a theoretical construct that is used to explain why some individuals fall ill after the occurrences of a stressful situations and some do not (p.1771).

Salutogenesis has its origins from the Latin 'salus', meaning health and the Greek 'genesis', meaning origins. It is a paradigm of psychology that developed in reaction to the perception that most other widely used paradigms are pathogenic, which is, based on discovering 'sources of illness'. "Psychology has been functioning mainly (but not completely) in a paradigm of pathogenic (Greek: pathos = disease; suffering) thinking" (Strűmpfer, 1990, p. 266). According to Strűmpfer (1990) salutogenesis aims to provide "an understanding of why and how some people find the strength to withstand and overcome pressures toward increasing entropy, whereas others do not, [which] is also likely to lead to ways of increasing the numbers of those who do" (p. 266). Salutogenesis views health and illness as being either ends of a continuum, position upon which indicates degree of wellness. According to Strűmpfer (1990) salutogenesis is based on a number of constructs

…that have developed independently but which seem quite clearly part of the new paradigm, namely Antonovsky's (1979, 1987) 'sense of coherence', Kobasa's (1982a) 'personal hardiness', Ben-Sira's (1985) 'potency', Thomas's (1981) and Colerick's (1985) 'stamina', and Rosenbaum's (1988) learned resourcefulness (p. 265).

These constructs all have in common the fact that they deal with "…'how people manage stress and stay well' (Antonovsky's 1987 subtitle)" (Strűmpfer, 1990, p. 265) and this emphasis on the maintenance and enhancement of wellness and prevention and treatment of illness emphasises their importance for research in health psychology. Other constructs linked to this paradigm include: Rotter's 'internal-external locus of control', Bandura's (1925) 'self-efficacy' and Pavlov's (1927) 'strength of the nervous system' (Strűmpfer, 2003). Strűmpfer (2003) also explored a number of psychological variables that make up the general concept of resilience.

Antonovsky's original construct 'sense of coherence' grew out of his clinical work with women who had survived Nazi concentration camps and emerged physically and psychologically well, in spite of considerable trauma (Bowman, 1996) and is defined as

> …a global [dispositional] orientation that expresses the extent to which one has a pervasive enduring though dynamic feeling of confidence that (1) the stimuli, deriving from ones internal and external environments in the course of living are structured, predictable and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement…In other words, it is an orientation to the world based on a feeling of confidence in the comprehensibility (makes cognitive sense); manageability (coping; meeting challenges); and meaningfulness (makes sense emotionally) of life experiences (Antonovsky, 1979, p.19).

"Rather than a coping 'style' within itself, a Sense of Coherence appears to be more an underlying world view which allows one to develop more active and adaptive coping styles when dealing with stress" (Bowman, 1996, p. 547). Antonovsky's work on a variety of general resistance resources (GRR's) such as physical and chemical GRR's, artefactual GRR's (health, clothing, food etc.), cognitive GRR's (intelligence, education), emotional GRR's, coping strategies, interpersonal relations and macrosocial GRR's (culture, religion) contributed to the construct SOC. "All GRR's have in common that they facilitate making sense out of the countless stressors with which we are constantly bombarded" (Antonovsky, 1993, p.725). As a result of repeated experiences of sense-making a 'sense of coherence' develops. This highlights the core role that the concept of 'meaningfulness' plays in coping with suffering, a topic also explored by Viktor Frankl (1985). Cross-cultural studies have been done which suggest that Antonovsky's SOC is a valid construct across cultures and studies linking childhood conditions and sense of coherence have also been done (Bowman, 1996).

Salutogenesis as a paradigm was later expanded by Strűmpfer as he explored more of Antonovsky's work and found that references to 'strength' appear throughout. Strűmpfer's later concept of Fortigenesis, a more embracing and holistic concept referring to the origins of psychological strength in general (Strűmpfer, 1990), based on the Latin 'to strengthen or reinforce' and the English derivative 'fortitude', meaning 'strength or courage in adversity or pain', incorporates within it the idea of salutogenesis.

Kobasa's (1979) term 'hardiness', which denotes a certain type of personality style that manages high stress well, originated from a study she did which compared people with high stress and illness levels to another group of people who had high stress levels but low levels of illness. Kobasa (1979) hypothesized that this hardy personality style is what helped these people to cope with stress better and what enabled them to maintain better physical and mental health levels. Hardiness consists of three cognitive factors associated with how people interpret certain events that occur in their lives:

- having a sense of control over their lives

This included a sense of autonomy in their decision-making ability, the ability to understand and incorporate the stress into an ongoing life plan, and a variety of coping skills.

- a sense that stress constitutes a challenge and not a crisis

This includes a sense that stress can bring growth and good change and the tendency to seek out change.

- a sense of commitment to areas of their lives

This included a belief system that assisted them to interpret stress as a challenge rather than as a threat, a sense of purpose that prevented surrender when stress arose, and involvement in positive social relationships.

Thus, people with hardiness tend to engage in transformational coping. In other words, when confronted with stress and change they become active determinants in the direction that the change is going to happen (Maddi & Kobasa, 1984).

3.2.14.2. Psychoneuroimmunology

The rise in power of Christianity in the Middle Ages and the Christian disregard for the physical in favour of the spiritual led to what is now termed the mind-body split. Although Western science has begun to recognise the problems associated with this way of thinking about people, it is still evident today. In the past few decades there has been a shift in thinking toward a more holistic approach to health, incorporating both physical and mental health. The 1980s brought about growth in the field of psychoneuroimmunology (PNI), which is the study of the interaction between emotion, the nervous system and the immune system (Compton, 2005). Early studies began to show links between these systems, however, there was still a great deal of scepticism from the medical community with the New England Journal of Medicine stating in 1985 that connections between disease and mental state were largely folklore (Compton,

2005). It was only in 1991 that a direct causal link was found between psychological stress and susceptibility to the common cold (Cohen, Tyrell & Smith, 1991). This study also found that the greater a person's social support network, the less likely they were to become ill. According to Compton (2005) "Currently, a substantial amount of research has found scientifically measurable relationhips between cognition, emotions, and the immune response" (p. 111). Studies have found that loneliness is one emotion in particular that can have significant detrimental effects on immune functioning, health and a sense of well-being (Brannon & Feist, 2000). Stress is related to a decrease in certain cells associated with immune functioning and that this effect is greater for people who have less social support and report more feelings of loneliness (Kiecolt-Glaser, Garner, Speicher, Penn, Holiday & Glaser, in Compton, 2005).

3.2.14.3. Social support and health

It is thought that social support has an impact on health in that it provides "a 'buffer' during stressful times and helps to decrease the negative effects of stress" (Compton, 2005). Social support has been found to increase feelings of security, confidence and hope. Empathy, which is found in supportive relationships, has also been found to decrease feelings of anger, hostility and aggression, which have associated with heart disease (Compton, 2005).

Spiegel, Kramer, Bloom and Gottheil (1989) were among the first to note the benefits of social support. Their study found that women with breast cancer who were in support groups tended to live an average of 18 months longer than those who were not in support groups. Since then a number of studies have found that social support has a significant impact on health. According to Compton (2005):

> The presence of social support has been associated with positive health
> outcomes such as greater resistance to disease, lower rates of coronary
> heart disease, faster recovery from heart disease and heart surgery, and

lower mortality. Social support can also help increase compliance with medical treatments, and may speed up recovery (p. 112).

A study by Berkman and Syme (1979) found that a lack of social support was as detrimental as smoking when correlated with mortality rates. Specifically with regards to women, social support during pregnancy and labour has been found to be associated with fewer complications and shorter delivery times (Nuckolls, Cassel & Kaplan, in Compton, 2005; Sosa, Kennel, Robertson, Klaus & Urratia, in Compton, 2005). Social support has also been found to be beneficial for women struggling with infertility. Participation in support groups and relaxation training programmes were found to significantly increase pregnancy rates (Kolt, Slawsby & Domar, 1999). With particular reference to men, specifically married men, the support of the partner and the belief that they are loved by their wife, has been found to be a better predictor of possible future angina, than physical factors such as cholesterol and blood pressure (Medalie & Goldbourt, in Compton, 2005). The perception of being loved by their wife has also decreased men's risk for stomach ulcers (Medalie, Strange, Zyzanski & Goldbourt, in Compton, 2005). The perception of having been loved as a child has also been associated with less risk for hypertension, heart disease, ulcers and alcoholism (Russel & Schwartz, in Compton, 2005).

3.2.14.4. Humour and health

Both having a sense of humour and the act of laughter itself have been associated with health benefits. Having a sense of humour and being able to laugh at oneself and/or the situation one finds oneself in have been shown to have positive correlations with more effective adjustment and higher levels of well-being (Valliant, 1977). The act of laughter has been found to increase infection-fighting antibodies, increase disease-killing cells and decrease blood pressure (Lefcourt, 2001). According to Compton (2005):

> …people who score high on a sense of humour scale also tend to
> score high on measures of optimism, extroversion, and capacity

for intimacy and scored low on neuroticism. High scorers also showed less negative self-esteem and tended to use better coping strategies to deal with stress (p. 115).

According to Lefcourt (2001) the overall effect of humour is that it enables people to better cope with stressful situations, to recover more swiftly from illness or injury, to deal more effectively with anxieties about dying, to cope with pain more easily, and lastly, humour has been found to have significant effects on immune functioning.

3.2.15. Conclusion

It can be seen that positive psychology has been a consideration for many decades, but that as a movement it has only recently begun to gain more widespread recognition. Positive psychology focuses on the aspects of human functioning that enable people to cope, be resilient and thrive and for this reason, was thought to be particularly relevant to a study on the experience of coping amongst HIV-positive African women.

3.3. OBJECT RELATIONS THEORY

3.3.1. Introduction and motivation for using object relations theory

The final theory to be considered is that of object relations theory, which is in fact an umbrella term for a number of distinct theories that share certain ideas about the development of the human psyche. Object relations theory is an influential conceptual model that was developed over the past 80 years in order to understand the more severe psychopathology previous psychodynamic theory focusing on neuroticism had failed to address (Ivy, 1990). There are a number of object relations theorists whose views diverge somewhat, however, there is common ground and it can be presented in a

simplified form as a unified approach (Ivy, 1990). A more formal definition of this theory is that it is a:

> psychoanalytic developmental account of how primary interpersonal relationships in the infant's external world become internalised, represented and metabolised at the level of fantasy into a nucleus of personal identity which, whether healthy or deficient, determines subsequent personality development and deformation (Ivy, 1990, p.3).

Object relations theory grew out the work of Freud, whose contribution to psychoanalysis was, in his own words, to 'disturb the sleep of the world' (Freud, 1933). His theory, based mainly on medical thinking, emphasised the role of instinctual drives and previous trauma as being the 'cause' of symptoms. He developed 'psychical analysis' as a means to rework previous trauma and 'cure' symptoms. Freud's theories can be said to be some of the most influential, however, the theorists that followed Freud and developed his ideas began to make shifts away from Freud's 'pleasure-seeking ego' to an ego that was 'object-seeking'. Freud's libidinally driven structural model was adjusted or abandoned in favour of a "'self-object' theory, in which parts of the self are seen in dynamic interaction with each other and complementary internal and external objects" (Fonagy, 2004, p. 83). According to Waddell (2002):

> Klein, and others, notably W.R.D. Fairbairn and D.W. Winnicott, traced a crucial developmental shift from anxiety about self-survival to concern for others, emotional responsibility and a desire to repair. With the linking of developmental to ethical concerns and matters of value, psychoanalysis became less instinct-bound and more interested in emotional life and meaning. This interest in the formative effect of early relationships became known as an "object relations" approach, a term which, albeit

clumsy, stresses the significance of the nature and quality of
relationship between self and other (p. xviii).

This exploration of infants' experiences of the world and relationships led to theories around infantile anxiety and the role of early relationships in the development of a self capable of healthy versus unhealthy or pathological functioning.

Due to the qualitative approach of this study, it was decided that the themes that emerged from the interviews would inform the choice of the specific theorists to be used in the interpretation and discussion of the themes. Allowing the themes to influence the theory used allows the data to lead the process of research, which is in line with a qualitative approach to research. The themes that emerged from the study, which will be discussed in a later chapter, included a number of areas of study covered by D.W. Winnicott, whose theory falls into the category of the British School of Independents. Although still falling under the umbrella category of object relations theories, the theorists in the British School should not be considered a unified approach. According to Fonagy (2004): "These workers do not subscribe to a single coherent framework; hence, their usual collective description as "the Independents" is probably highly appropriate" (p. 93).

Other theorists mentioned in this section of this study will include Melanie Klein and Wilfred Bion. While Winnicott's theory is considered an object relations theory that holds a more romantic view of humankind, the Klein-Bion model is considered to hold a more classical view (Akhtar, 1992). The classic view emphasises the reign of reason as the essence of being human, while the romantic view is considered to value authenticity and spontaneity (Akhtar, 1992). While a focus on striving toward autonomy is considered to be a part of the classical view, it is evident in both approaches, as can be seen in Winnicott's description of the infant's journey from dependence to independence.

The classic view considers humans to be inherently limited but partly able to overcome their tragic flaws, to become "fairly decent" (Akhtar, 1992, p. 320) and psychopathology is understood largely in terms of conflict. The romantic view, however, holds a view of

people as capable of intrinsic good, but considers development as vulnerable to restriction through circumstance. In the romantic view psychopathology is regarded as maladjustment due to deficit (Akhtar, 1992). According to Fonagy (2004):

> The romantic view is more optimistic, seeing human beings as full of potential and the infant as ready to actualize the blueprint of his destiny. The classic view is more pessimistic. Conflict is seen as embedded in normal development. There is no escape from human weakness, aggression, and destructiveness, and human life is an unending struggle against the reactivation of the inevitable vicissitudes of infancy. In the romantic view there is primary love; in the classic view it is seen as a developmental achievement (p. 83).

It is important to note, however, that despite the differences in the viewpoints of these theories, Winnicott was influenced by both Klein and Bion's theories. The influence of Kleinian 'instinct theory' on Winnicott's theories can be seen in Winnicott's view that the infant's predisposition has a highly significant role in determining the nature of the mother-infant relationship and his theory of the development of a false self in reaction to caregivers' inability to contain certain of the infant's 'internal excitements' (Fonagy, 2004).

While important concepts such as splitting, projection and projective identification, which were described by Klein (1935) and later refined by Bion (1959) will be discussed in this section, the focus will be on Winnicott's (1958, 1960a, 1960b) theory as his 'romantic' object relations theory resonates more with the positive psychology focus of this study. Winnicott's theory also covers an inherent desire to develop a sense of self (1960b), the capacity to be alone (1958), loss and mourning (1954) and dependence-independence (1965) all of which emerge as themes from the interview material.

The fact that Winnicott's theory focuses on the development and structure of the self, and considers this self a filter for all experience, makes it relevant to this study. It is proposed that the selves (and hence, the internal object representations determining these selves) of the women who participate, will form an integral part (albeit on a different conceptual level) of the understanding of strength, resilience and sense of coherence with regards to living with HIV/AIDS. Winnicott (1965) describes a 'self' that is ready to die, the development of which he believes is reliant on a 'good enough' mother during the holding phase of infant development. Thus, the assumption that object relations theory makes about the nature of the world – that the quality of a person's earliest relationships impacts on his/her personality development, his/her ability to cope and even on his/her readiness for death, is relevant to a study on coping with illness and death.

The themes of feeling alone and at times, choosing to be alone, emerge from the interview material and while Fairbairn (1952) extrapolated the pathological wish to be alone, Winnicott (1958) described the wish to be alone as the most important sign of maturity in emotional development:

> It is probably true to say that in psycho-analytical literature more has been written on the fear of being alone or the wish to be alone than on the ability to be alone; also a considerable amount of work has been done on the withdrawn state, a defensive organization implying an expectation of prosecution. It would seem to me that a discussion on the positive aspects of the capacity to be alone is overdue (p.29).

Winnicott's (1958) 'capacity to be alone' may be linked to the important developmental tasks of separation and individuation, which also emerge as crucial to this study. These will be discussed in greater depth later in this chapter.

The theme of loss is discussed by Winnicott (1954) and emphasizes that an individual's capacity to manage loss of any kind, and ultimately death, is related to their early

development of the capacity to bear psychic reality (Waddell, 2002). It is in this section that there is overlap with important concepts discussed by Klein (1935) and Bion (1959).

Lastly, object relations theory is also suited to qualitative research as it encompasses by its very nature an appreciation of the influence of context on human functioning. According to Fonagy (2004) the rise of object relations theories in psychoanalysis was associated with an increasing move towards an experientially based perspective: "These approaches inevitably emphasize phenomenological constructs, such as the individual's experience of himself or herself, and theory has become increasingly concerned with relationships" (Fonagy, 2004, p. 82). The romantic school of object relations theories views human development as integrally intertwined with both personal relationships and those with society at large. Winnicott (1965) states: "Cultural influences are of course important, vitally important; but these cultural influences can themselves be studied as an overlap of innumerable personal patterns" (p.15).

3.3.3. Klein's paranoid-schizoid and depressive positions

These two positions are considered to be one of Klein's (1946) most important contributions to psychoanalysis and are two groupings of particular anxieties and defences (Steiner, 1990). The move from the paranoid-schizoid to the depressive position is associated with an increasing integration of the self and object relations and the achievement of the depressive position is linked to a greater wholeness of the self. According to Steiner (1990): "Alongside this comes a shift in preoccupation with the survival of the self to a recognition of dependence on the object and a consequent concern with the state of the object" (p. 46). Klein (1946) describes the paranoid-schizoid position as a time when the immature ego is threatened by primitive anxieties, which leads to the use of the more primitive defences such as splitting, projective identification and idealization. In this position the ego splits into two, one containing aspects of the self considered good, the other aspects of the self considered bad and these two parts are kept as far from each other as possible. Aspects of each of these selves are

then projected onto others creating good or loving and bad or persecutory object relationships, which then tend to alternate. Steiner (1990) explains:

> Klein believed that the individual is threatened by sources of destructiveness from within, based on the death instinct, and that these are projected into the object to create the prototype of a hostile object relationship. The infant, hates, and fears the hatred of, the bad object, and a persecutory situation develops as a result. In a parallel way primitive sources of love, based on the life instinct, are projected to create the prototype of a loving object relationship (p. 47).

According to Klein (1946) the splits in the self and the object result in the self and the object being experienced as parts (breast, hand, face) rather than as an integrated whole. These splits in the ego also mean it is poorly integrated over time, which results in there being no memory of a good object when it is not present. Instead, when the good object is absent, it is not perceived as a loss but rather as having been replaced by a persecutory object. Segal (1957) writing on Klein's positions, states that the use of these primitive defences, particularly projective identification, can result in confusion between the self and the object, as well as between the symbol and the thing symbolized. On the other hand, when objects begin to be recognized as whole, an important developmental shift is seen to take place, in that ambivalent impulses begin to be directed toward the object (Steiner, 1990). Steiner (1990) states:

> The infant comes to recognize that the breast which frustrates him is the same one which gratifies him and the result of such integration over time is that ambivalence – that is, both hatred and love for the same object – is felt. These changes result from an increased capacity to integrate experiences and lead to a shift in primary concern from the survival of the self to a concern for the object upon which the individual depends (p. 48).

According to Segal (1957) Klein's theory highlights the importance of normal splitting. In healthy development, normal splitting helps to organize chaotic experiences and provides primitive ego structuring and it is at this stage that the alternation between persecutory and idealized states are seen. This allows time for ego strengthening to occur, which then, in turn, allows for greater integration and a greater tolerance of ambivalence. As the splits lessen, the depressive position is gradually achieved. According to Klein (1957) it is when splitting as a defence breaks down and the entire personality is flooded with primitive anxiety that clinical states of severe pathology are observed. Intense fear and confusion is evident in these states.

Klein (1935) writes about necessary mourning that has to occur during the achievement of the depressive position and that this is related to separation or differentiation. It is the process that involves a changing experience of the object in relation to the self i.e. moving from 'I am the object' to 'I have the object' to 'I cannot control the object'. Steiner (1990) highlights the fact that this realization is experienced as a loss and that a process of mourning is necessary. In the initial stages of this mourning, where the loss of the object is denied, a type of projective identification occurs where the individual attempts to possess the object by identifying with it (Klein, 1952). Although the object is now seen as separate, there are still attempts to possess it entirely. However, this is eventually also given up in the mourning process, when the individual has to face his/her inability to control the object or what happens to it. Steiner states:

> A critical point in the depressive position arises when the task of relinquishing control over the object has to be faced. The earlier trend, which aims at possessing the object and denying reality, has to be reversed if the depressive position is to be worked through, and the object is to be allowed its independence. In unconscious phantasy this means that the individual has to face his inability to protect the object…and his awareness that his love and reparative wishes are insufficient to preserve his object

which must be allowed to die with the consequent desolation, despair and guilt (p. 53).

3.3.3. Winnicott's theory of development: from dependence to independence

Winnicott (1965) is often criticised for his controversial claim that the strength or weakness of an infant's ego is a direct function of the mother's capacity to respond appropriately to the absolute dependence of the infant in the earliest phases of life. This criticism stems from the assertion that this mother-centrism leads to mother-blaming. However, while subsequent theories, such as attachment theory, have examined the influence of other relationships, namely the father-child and alternative caregiver-child relationships, Winnicott (1960a) was one of the first to strongly acknowledge the importance of external relationships in the development of the self.

According to Fonagy (2004) Winnicott's theory places "the self as the focus of the psychology of the mind, seeing self and object representations as intertwined and reciprocally influencing agents, construing relationships as organized to safeguard self structures" (p. 102). Although Winnicott (1960b) acknowledges the role of nature or biology, which he refers to as including an inherited "tendency towards growth and potential" (p. 43), his theory focuses primarily on the role of 'nurture' in development, Winnicott (1960b) states: "There is no such thing as an infant, meaning, of course, that whenever one finds an infant one finds maternal care, and without maternal care there would be no infant" (p. 39). With this statement he highlights the importance of early relationships with regards to development of the individual and asserts the notion that it is not sufficient to merely regard the environment as important in the early development of the infant, but rather to acknowledge the entanglement of infant development and maternal care. According to Winnicott (1960b):

> One half of the theory of the parent-infant relationship concerns the infant, and is the theory of the infant's journey from absolute

dependence, through relative dependence, to independence, and, in parallel, the infant's journey from the pleasure principle to the reality principle, and from autoeroticism to object relationships. The other half of the theory of the parent-infant relationship concerns maternal care, that is to say the qualities and changes in the mother that meet the specific and developing needs of the infant (p. 42).

According to Winnicott (1965) individuals inherit a maturational process, which together with a facilitating environment allows for development. Winnicott's (1965) theory focused on providing a developmental description of the origins of the self within this facilitating environment, namely the infant-caregiver relationship. He described a time of primary maternal preoccupation, when the mother is focused entirely on her new infant due to heightened sensitivity to herself, her body and her infant, creating a unique unity between them. From this initial unity between mother and infant, Winnicott (1965) described three functions that he believed facilitate the development of a healthy self, namely, holding, handling and object presenting or relating. Winnicott (1965) states:

The individual proceeds from absolute dependence to relative independence and towards independence. In health the development takes place at a pace that does not outstrip the development of complexity in the mental mechanisms, this being linked to neurophysiological development. The facilitating environment can be described as holding, developing into handling, to which is added object-presenting. In such a facilitating environment the individual undergoes development which can be classified as integrating, to which is added indwelling (or psychosomatic collusion) and then object-relating (p. 175).

The main body of Winnicott's (1960b) theory explores the time before a separateness of self has occurred and before there has been any structuring of the ego. "Anxiety at this stage is not castration anxiety or separation anxiety; it relates to quite other things, and is,

in fact, anxiety about annihilation" (Winnicott, 1960, p. 41). Winnicott (1960) states that annihilation anxieties are associated with pain that is of psychotic quality and intensity. Hence, the first function of the mother-infant relationship that Winnicott (1965) considered as essential to development of the self was holding, in which these 'annihilation' anxieties are kept to a minimum by the mother, which he viewed as necessary in order for the infant to slowly develop their ability to manage these anxieties, allowing for an integration of sensorimotor elements.

Winnicott (1960b) believed that the infant, at first, has no concept of being separate from the mother and is merged with her. During the initial holding phase of the mother-infant relationship, the infant's ego slowly becomes more structured and integrated, which allows the infant to begin to experience anxiety associated with disintegration. According to Winnicott (1960b) in these early stages of the infant-parent relationship, anxiety relates to the threat of annihilation. While the aim of the holding environment is to allow the infant to develop a 'continuity of being', annihilation anxieties are activated when the infant experiences interruptions to this continuity of being and has to react. The holding environment aims to keep these interruptions to a minimum. "Under favourable conditions the infant establishes a continuity of existence and then begins to develop sophistications which make it possible for impingements to be gathered into the area of omnipotence" (Winnicott, 1960b, p. 47).

While Winnicott's (1965) emphasis on the importance of maternal care can be seen in his assumption that sensitive caretaking shields the infant from unbearable mental experience in the form of primitive anxiety while the infant is in the vulnerable process of developing from an unintegrated to an integrated state, it is the assumptions regarding the internal state of the infant that shows the strong influences of Klein and Bion on Winnicott's theory (Fonagy, 2004). Klein's (1946) work focused on the infant in its earlier stages of development and clarified the interplay of primitive anxieties and the development of defences. In the first stage of mental development the infant develops early defences against primitive anxieties. These defences are known as splitting, projection and introjection. Klein (1946) describes aggressive and destructive impulses

that are more deeply rooted than the hate and anger associated with reactions to frustration that occur in later stages of development. Winnicott (1960b) also writes about the development of ego mechanisms of defence in psychodynamic theory and how these defences were initially thought of as being organised in relation to anxiety derived either from instinct tension or object loss. Hence, the influences of Klein and Bion can be seen in Winnicott's (1965) view that:

> …the infant's predisposition has a highly significant role in determining the nature of the mother-infant relatumship. Thus, matemal care is not the only determinant of the holding environment. The stability and balance within the baby itself, the initial balance with which it starts life, contributes to the likely success of maternal care. This is similar to Bionian notions of the infant's envious attack on containment (Fonagy, 2004, p. 103).

Klein's influence can be seen in Winnicott's (1965) acknowledgement of instinct theory. "Winnicott…does not consider relationships to be independent from instincts and has an integrated formulation where instincts and object relationships are intricately interwoven" (Fonagy, 2004, p. 103). Winnicott's (1965) acknowledgement of instincts can be seen in his theory on the development of a false self in cases where the caregiver is unable to contain the infant's traumatic internal excitements. When overwhelmed the infant uses primitive defences, such as splitting, which results in various of their instinctual tensions being experienced as not a part of the self. Thus, Winnicott's (1965) 'good enough' mother needs to be able to permit the infant's spontaneous expressions of needs. Mothers who are not sufficiently able to do this communicate to the infant that their impulses and expressions are dangerous, resulting in the child needing to split off further aspects of their 'true' selves, developing a 'false' self acceptable to the mother.

However, Winnicott (1965) also appeared to view the development of a personal defence system as an integral part of the child's journey to independence. Winnicott (1960b) explains that the formation of these particular defences presupposes a separateness of self

and a structuring of the ego. "In psychoanalytic theory ego mechanisms of defence largely belong to the idea of a child that has independence, a truly personal defence organisation" (Winnicott, 1960, p. 42). Hence, it can be seen that while Winnicott (1965) viewed the development of defences as important to the infant's developing independent self, he considered the excessive need for defence as unhealthy.

The next function of maternal care is that of handling, which according to Winnicott (1960b) leads to an 'indwelling' of the child's psyche in its own body. According to Winnicott (1960b) where maternal care is successful, the infant achieves a 'continuity of being' which is the basis of ego-strength:

> Associated with this attainment is the infant's psychosomatic existence, which begins to take on a personal pattern; I have referred to this as the psyche indwelling in the soma. The basis of this indwelling is a linkage of motor and sensory and functional experiences with the infant's new state of being a person. As a further development there comes into existence what might be called a limiting membrane, which to some extent (in health) is equated with the surface of the skin, and has a position between the infant's 'me' and 'not-me'. So the infant comes to have an inside and an outside, and a body-scheme. In this way meaning comes to the function of intake and output; moreover, it gradually becomes meaningful to postulate a personal or inner psychic reality for the infant (Winnicott, 1960b, p. 45).

According to Winnicott (1960b) this is a crucial stage in the infant's development from dependence to independence. The build up of memories of reliable maternal care allow the child to survive the gradual realisation that the infant is in fact separate from the mother and is an individual in his own right. "This change is closely bound up with the infant's change from being merged with the mother to being separate from her, or to relating to her as separate and 'not-me'" (Winnicott, 1960, p. 45). This development is

related to the phase of 'living with'. However, if there are too many interruptions due to maternal failure, the ego is weakened and a 'continuity of being' or sense of self is not sufficiently established. "In the extreme case the infant exists only on the basis of a continuity of reactions to impingements and of recoveries from such reactions" (Winnicott, 1960b, p. 52).

Winnicott's (1960b) third function of maternal care, namely object relating, results in the establishment of a human relationship. This is said to occur through 'optimal maternal failure' which is where the unity between the mother and infant due to the mother's primary maternal preoccupation, which creates the illusion that "…the mother responds accurately to his gesture because she is his own creation, that is, a part of him" (Fonagy, 2004, p. 94), is slowly disappointed. Hence, Winnicott's (1960b) 'good-enough' mother is a mother who can provide manageable amounts of maternal failure, promoting growth of the child's independent self. Winnicott's idea of optimal maternal failure is: "…consistent with the observation of attachment researchers that moderate degrees of maternal involvement are preferable to highly contingent responses... Moderate levels of acceptance…and maternal involvement…are more beneficial to growth than perfect matching" (Fonagy, 2004, p 96). These maternal failures challenge the infant's experience of being merged with the mother and instead of experiencing her response to his/her needs as magical omnipotence, she is perceived as separate (Winnicott, 1971). Hence, the third maternal function of object relating is the development of the infant's capacity for separation and perception of his/her relationship with his/her mother as no longer omnipotent, but rather genuine (Winnicott, 1971). Winnicott (1971) emphasizes, though, that maternal failure must not happen too soon. If the infant is prematurely faced with the mother's independence as a person, the infant would then be forced "…to negotiate the "me and not me" distinction before he acquired sufficient experiences of being omnipotent to form the ego nuclei that will, in time, become integrated in the real experience of the "I" (the true self)" (Fonagy, 2004, p. 97).

According to Winnicott (1965) the self of a neonate does not yet exist, but "…the true self is rooted in the summation of a kind of sensorimotor aliveness that is assumed to

characterize the neonate's mental world" (Fonagy, 2004, p. 96). According to Winnicott (1960a) the emergence of the true self is dependent upon the development of self-awareness, which results from the negotiation of separation between the mother and the infant. The infant's experience of his/her feelings and perceptions as being distinct from those of others allows for the the differentiation of me from not-me (Winnicott, 1960a).

3.3.4. Fear of Death

Winnicott (1960b) differentiates between annihilation and death anxieties. According to Winnicott (1960b): "Death has no meaning until the arrival of hate and of the concept of a whole human person" (p. 47). Only when a person can be perceived of as alive and separate, can the infant begin to contemplate death, hence the idea of death is linked to later developmental stages.

When discussing the fear of death, Winnicott (1965) compares it to the fear of breakdown, stating: "Little alteration is needed to transfer the general thesis of fear of breakdown to a specific fear of death" (p. 179). Winnicott (1965) describes breakdown as a vague term that can be taken to mean a failure of defence organization and a reversal of the maturational processes and that "…clinical fear of breakdown is *the fear of a breakdown that has already been experienced. It* is a fear of the original agony which caused the defence organization which the patient displays as an illness syndrome" (p. 176). This breakdown that has already been is carried around in the unconscious and for some reason cannot be integrated into the ego. "The ego is too immature to gather all the phenomena into the area of personal omnipotence…the original experience of primitive agony cannot get into the past tense unless the ego can first gather it into its own present time experience and into omnipotent control" (Winnicott, 1965, p. 177), however, some things we can never gather into the omnipotent control of the ego, because "the ego cannot organize against environmental failure in so far as dependence is a living fact" (Winnicott, 1965, p. 174). .

With specific reference to the fear of death, Winnicott (1965) states that this fear is common and that defences against it, for example denial, are often incorporated into the teachings of various religions of an afterlife. When fear of death is severe, the promise of an afterlife does not comfort, because the individual is compelled to look for death – a death that has already happened in the psyche but that was not experienced. Winnicott (1986) states that: "Many men and women spend their lives wondering whether to find a solution by suicide, that is, sending the body to death which has already happened to the psyche" (Winnicott, 1965, p. 179). This 'death of the psyche' to which Winnicott (1965) refers can be best understood when the influences of Winnicott's understanding of loss and mourning are explored. This will be done under the section on loss and mourning.

3.3.5. The Manic Defence

Winnicott (1935) states that the use of the manic defence to a certain degree is 'normal'. As a society, our lively shows and dances, could be viewed as a denial of deadness and a defence against the depressive 'death inside' ideas. "What about such things as the wireless that is left on interminably? What about living in a town like London with its noise that never ceases, and lights that are never extinguished? Each illustrates the reassurance through reality against death inside, and a use of a manic defence that can be normal" (Winnicott, 1935, p. 131). Winnicott (1935) writes about Klein's manic defence, stating that a part of the manic defence is an individual's inability to give full significance to his or her inner reality and an inability to tolerate depressive anxiety and doubt. According to Winnicott (1935) the manic defence:

> …shows in several different but interrelated ways, namely:
> - Denial of inner reality.
> - Flight to external reality from inner reality.
> - Holding the people of the inner reality in 'suspended animation'.

- Denial of the sensations of depression – namely, the heaviness, the sadness – by specifically opposite sensations, lightness, humorousness, etc.
- The employment of almost any opposites in the reassurance against death, chaos, mystery etc., ideas that belong to the fantasy content of the depressive position (p. 132).

"The term manic defence is intended to cover a person's capacity to deny the depressive anxiety that is inherent in emotional development…" (Winnicott, 1935, p. 143). An important aspect of Winnicott's (1935) definition of the manic defence is the fact that he considers the ability to tolerate depressive anxiety as being essential to emotional development.

> But it is characteristic of the manic defence that the individual is unable fully to believe in the liveliness that denies deadness, since he does not believe in his own capacity for object love; for making good is only real when the destruction is acknowledged (Winnicott, 1935, p. 132).

Winnicott (1935) refers to the opposite of depressive as ascensive, as it successfully defends against the aspects of depression that imply a heaviness, which can be seen in the phrases: "heaviness of heart, depth of despair, that sinking feeling" (p. 135). "One has only to think of the words 'grave', 'gravity', and of the words 'light', 'levity', 'levitation'; each of these words has double meaning. Gravity denotes seriousness, but is also used to describe a physical force. Levity denotes devaluation and joking as well as a lack of physical heaviness" (Winnicott, 1935, p. 135).

> The word ascensive brings into the foreground the significance of the Ascension in the Christian religion…Each year the Christian tastes the depths of sadness, despair, hopelessness, in the Good Friday experiences. The average Christian cannot hold the

depression so long, and so he goes over into a manic phase on Easter Sunday. The Ascension marks recovery from depression (Winnicott, 1935, p. 135).

The manic defence is aimed at defending against pain, sadness, guilt and worthlessness, but denies the individual the value of reaching towards what is a part of their personal inner or psychic reality (Winnicott, 1935). Importantly, Winnicott (1935) writes that mourning cannot happen when the manic defence is in use.

> In the manic defence everything serious becomes negated. Death becomes exaggerated liveliness, silence becomes noise, there is neither grief nor concern, neither constructive work nor restful pleasure. This is the reaction formation relative to depression and it needs to be examined as a concept in its own right. Its presence clinically does imply that the depressive position has been reached, and that the depressive position is being held in abeyance and negated rather than lost (Winnicott, 1954, p. 272).

This implies that the manic defence may not necessarily be pathological, but rather protective as long as it does not continue indefinitely. This can be more clearly seen in Winnicott's (1954) understanding of the role of Klein's (1935) depressive position in relation to loss and mourning.

3.3.6. Loss and mourning

Freud's (1917) work in this area is regarded as one of his greatest contributions to psychoanalysis. He emphasized that the painful facing of the reality of the totality of the loss is the work of mourning and that acknowledgement of the loss leads to enrichment of the mourner. Freud (1917) states:

> Each single one of the memories and situations of expectancy
> which demonstrate the libido's attachment to the lost object is
> met by the verdict of reality that the object no longer exists; and
> the ego, confronted as it were with the question whether it shall
> share this fate, is persuaded by the sum of the narcissistic
> satisfactions it derives from being alive to sever its attachments
> to the abject that has been abolished (p. 245).

Initially, when the loss of the object is unbearable, the mourner attempts to deny the reality of the loss by identifying with the lost object. This identification with the lost object then implies that the experience of confronting the loss involves for the mourner, a sense that if they let go of the lost object, they will not survive it. According to Steiner (1990) mourning involves facing this paradox: "If it is successfully worked through, it leads to the achievement of separateness between the self and the object because it is through mourning that the projective identification is reversed and parts of the self previously ascribed to the object are returned to the ego" (Steiner, 1990, p. 55).

As discussed previously, the depressive position can be described as the stage of emotional development where the individual develops the capacity to tolerate both the good and bad in one whole person. Winnicott (1954) relates this to the infant's realisation that the mother who satisfies, whom the infant loves, is the same mother who frustrates, whom the infant hates. This is often referred to as the capacity for ambivalence. The inability to tolerate ambivalence results in continued use of the more primitive defences such as splitting, in order to keep the good and bad separate. "Melanie Klein's work has enriched the understanding Freud gave us of reaction to loss. If in an individual the depressive position has been achieved and fully established, then the reaction to loss is grief or sadness. Where there is some degree of failure at the depressive position, the result of loss is depression" (Winnicott, 1954, p. 275). According to Freud (1917) when a loss is experienced, the object lost is introjected. Internally it is subjected to the more persecutory forces i.e. anger and hatred. If the depressive position, according to Klein (1935) was not yet achieved, and the individual is

not yet able to tolerate both negative and positive feelings towards an object, the balance of forces internally is disrupted and an overall internal deadening produces a depressed mood. This depression, according to Winnicott (1954), can be healing as it provides defences and time against an overwhelming pain, allowing for the loss to be more slowly worked through. In individuals in which the depressive position was achieved, there are sufficient memories of good experiences that allow the individual to continue without the actual object. "Love of the internal representation of an external object lost can lessen the hate of the introjected loved object which loss entails. In these and other ways mourning is experienced, and worked through, and grief can be felt as such" (Winnicott, 1954, p. 275).

The depressive position is something that is often only fully reached later in life, and is a stage that often needs revisiting. Trauma and other life experiences can evoke a reworking of the depressive position. "…the subject of the depressive position in normal development is one that cannot be left aside; it is and it remains *the problem of life* except in so far as it is reached" (Winnicott, 1954, p. 277).

3.3.7. Loneliness and the capacity to be alone

Moustakas (1996) differentiated two types of loneliness: existential loneliness, which inevitably is part of human experience, and loneliness of self-alienation and self-rejection. While the former he considered necessary for a person to become fully aware of himself as an isolated and solitary individual, the latter he considered a vague and disturbing anxiety: "…in loneliness anxiety man is separated from himself as a feeling and knowing person" (p 24). Existential loneliness is considered an unavoidable and even valuable element of humanness. Wolfe (1941) discusses the inevitability of real loneliness as a part of genuine experience and an intrinsic condition of existence. He believed that it is necessary because out of these depths of despair and feelings of complete impotency comes the discovery of unique ways of being aware and expressing experience. However, the loneliness anxiety that Moustakas (1996) describes is

considered 'pathological' and is attributed to early childhood deprivation as well as social ills. Loneliness anxiety or a fear of loneliness is often attributed to changes in social patterns. May, Angel and Ellenberger (in Moustakas, 1996) state that man has lost his experience of neighbourliness and community life and thus experiences a feeling of alienation and estrangement from the human world about him. Other theorists also support the idea that feelings of loneliness have an earlier, more intrapsychic root; this can be described as follows:

The experience of loneliness has a significant developmental history that begins in infancy, when the infant's needs for contact and relatedness are not met. This experience of loneliness then emerges throughout crucial stages of development. Sullivan (1953) discusses various needs that occur in human development that relate to the experience of loneliness. The first is the need for tender contact and protective care in infancy and early childhood. When the child does not obtain the needed adult presence and participation, loneliness results. According to Sullivan (1953) the greater the intensity of separation, the greater the development of the child's sense of isolation and parental rejection. This sense of isolation is especially threatening in children, due to their inability to care for themselves. The possibility of being abandoned is a matter of life and death (Fromm, 1941). This is supported by Moustakas (1996), who states that loneliness anxiety is:

> …an exceedingly unpleasant, driving experience, resulting from inadequate fulfilment of the need for human intimacy – beginning in the early years with the failure to establish rich contact with the living, extending to the frustration of the need for tenderness and protective care, and into adult years when there is a failure to meet others on a genuine, fundamental, loving basis (p. 27).

Much of the work done in the field of psychodynamics is around three-body and two body relationships. Three-body relationships encompass the Oedipal theories while two-

body relationships cover an earlier time when the focus was on the infant-mother relationship. With regards to one-body relationships, Winnicott (1958) states:

> The capacity to be alone is either a highly sophisticated phenomenon, one that may arrive in a person's development after the establishment of three-body relationships, or else it is a phenomenon of early life which deserves special study because it is the foundation on which sophisticated aloneness is built (p. 30).

According to Winnicott (1958) the capacity to be alone is founded on a paradox, which is that the capacity to be alone develops in the presence of another. Winnicott (1958) states:

> Although many types of experience go to the establishment of the capacity to be alone, there is one that is basic, and without a sufficiency of it the capacity to be alone does not come about; this experience is that of being alone, as an infant and small child, in the presence of the mother…the capacity to be alone depends on the existence of a good object in the psychic reality of the individual (p. 30 - 32).

Good-enough mothering is a repetition of satisfactory interactions that allows the infant to build up a belief in a benign environment:

> In the course of time the individual introjects the ego-supportive mother and in this way becomes able to be alone without frequent reference to the mother or mother symbol…in the course of time the individual becomes able to forego the actual presence of a mother or mother-figure…gradually, the ego-supportive environment is introjected and built into the individual's personality, so that there comes about a capacity to be alone (Winnicott, 1958, p. 32-36).

"When alone in the sense that I am using the term, and only when alone, the infant is able to do what in an adult would be called relaxing" (Winnicott, 1958, p. 34). This comment highlights the importance of the introjection of a good-enough mother, as this is what allows for the ability to self-sooth or relax when alone. The capacity to be alone also allows for important self-reflection: "It is only when alone…that the infant [or adult] can discover his own personal life" (Winnicott, 1958, p. 34). So while the capacity to be alone is significant in terms of the ability to cope with times of being alone in later life, it is also paradoxically significant in terms of the ability to sustain relationships.

Winnicott (1958) refers to the relationship between the mother and the infant as being significant for the development of ego-relatedness. "It will be seen that I attach great importance to this relationship, as I consider that it is the stuff out of which friendship is made" (Winnicott, 1958, p. 33). This implies that the mother-infant relationship and the quality of ego-relatedness that develops may have implications for the quality of future friendship relationships from which the individual may require support. Sustained relationships require both the ability to 'be with' as well as 'be alone' from time to time. It is the ego-relatedness or ability to hold a positive mental representation of the other when apart that promotes relatedness.

According to Fonagy (2004) Winnicott makes a critical point concerning sensitivity in his "often misunderstood and somewhat paradoxical assertion that relatedness is born of the experience of being alone in the presence of somebody else" (p. 98). Fonagy (2004) states that Winnicott's assertion is based on three simple qualities of the holding (sensitive caregiving) environment. The first is that a sense of safety must be felt by the infant when experiencing the inner world. This is achieved through accurate mirroring of the infant's internal states by the mother (Winnicott, 1958). Bion's (1959) concept of containment also helped to elucidate how this mirroring supports the infant's developing ego. The second assertion that Winnicott (1958) makes that is related to how the holding environment enables ego-relatedness to develop is that the infant should only gradually be exposed to external events. If the caregiver is unable to manage mirroring and instead the infant is exposed to the caregiver's defensive reaction, the caregiver's defense is then

internalized in place of the child's actual experience and becomes the content of the experience of the self (Fonagy, 2004). According to Fonagy (2004) Winnicott's third assertion concerns the infant's opportunity to generate spontaneous creative gestures and the importance of the caregiver's acknowledging of the goalorientedness of the infant's physical being, which lends coherence to the infant's experience of body. "If handled satisfactorily, the infant looks at the mother's face rather than breast. His concerns with mind and meaning can override his preoccupation with his physical needs" (Fonagy, 2004, p. 99). Thus, the holding environment, if good enough, i.e. if the caregiver is perceived as an unobtrusive other, the infant experiences a continuity of being and then the true self can develop, which allows for true ego-relatedness (Winnicott, 1958).

3.3.8. False self development

Winnicott's (1960a) theory also covers environmental failure and the infant's reaction to it, namely the development of a false self. External impingements in the form of the caregiver's defensive structures and the "substitution of the gestures of the other for the gestures of the self" (Fonagy, 2004, p. 101) results in the development of a false self structure (Winnicott, 1960a). In other words, when the caregiver is overwhelmed by and cannot contain certain of the infant's internal experiences, the infant begins to regard these internal experiences as unacceptable and learns to hide and repress them. Instead a false self is developed that consists of the more acceptable parts of the self and acceptable internal experiences. Although this false self "performs and complies", it tends to be "fragile, vulnerable, and phenomenologically empty" (Fonagy, 2004, p 102). According to Fonagy (2004) a false self tends to develop in cases of preoccupied parenting, where there is an "invalidation of the infant's creative gestures" (p. 102). Fonagy (2004) states: "Winnicott conceptualizes the infant's reactions to this as the self acquiescing, hiding its own gestures, undermining its own ability. The false self serves to hide and protect the true self" (p. 102).

3.3.9. Bion's concept of thinking as containment

Containment is often inaccurately equated with Winnicott's (1958) notion of holding. Whereas holding or the holding environment is external, sensuous and positive or growth-promoting, the container is internal, non-sensuous and actively destructive or integrating. According to Bion (1959) the personality is constituted out of the dual elements of container/contained and that thinking and thoughts can be seen also to be in dynamic interaction as container/contained. Whereas Freud's theory was based on the pleasure principle, Bion (1959) believed that the motivating factor behind human behaviour was emotional growth. Bion (1962) developed Klein's (1946) concept of projective identification and stated that projective identification within limits was normal. His idea regarding container/contained seems then to be associated with his notion that there is "…a normal projective identification, without defining the limits within which normality lies, and that associated with introjective identification this is the foundation on which normal development rests" (p. 312).

In object relations, what is thought to make up the relation or link between objects is emotion or feeling, however, Bion (1962) hypothesized another link between objects, namely, thinking. Bion's 'thinking' is not referring to cognitive processes of the brain but rather to the process by which an individual attempts to know himself or another. According to O'Shaugnessy (1981): "His concern with thinking is as a human link, the endeavour to understand, comprehend the reality of, get insight into the nature of, etc., oneself or another. Thinking is an emotional experience of trying to know oneself or someone else" (p. 81).

Bion (1962) is always aware in his writing that knowing is an endeavour that will always contain doubt as his comment "How can one know anything?" shows (p. 48). However, 'thinking' is the attempt to know or try to remember painful emotional experience. Bion (1962) used the letter K to symbolize this attempt to know painful experiences, which he conceived of as a process of continually, actively engaging in the emotional experience of finding an evolving truth.   He allocated the symbol –K to the opposite of K, which he

conceived of as a determination not to know or experience anything. According to Bion (1962) "…an emotional experience that is felt to be too painful may initiate an attempt either to evade or modify the pain according to the capacity of the personality to tolerate frustration" (p. 48). According to Bion (1962) when there is "a need to be rid of emotional complications, of awareness of life and of a relationship with live objects" (p. 11), knowledge of painful internal and external reality is evaded. According to Bion (1962) when reality is evaded meaning can deteriorate and the capacity for symbolization may collapse. Bion (1962) states that without an awareness of life and one's emotions tension is experienced, misunderstandings are common, there can be failures to remember and emotional experience can become stripped of significance. At these times, this state of confusion is held to be preferable to understanding and achieving a coherent representation and integration of experience. According to Bion (1962): "The attempt to evade contact with live objects…leaves the personality unable to have any relationship with any aspect of itself that does not resemble an automaton" (p. 13). Bion (1962) believed that the struggle between the desire to know and understand and the desire to evade this knowing and understanding is as crucial to an understanding of mental life as love and hate. Interestingly, this struggle is echoed by Jung (1933) who states:

> Every one of us gladly turns away from his problems; if possible, they must not be mentioned, or, better still, their existence is denied. We wish to make our lives simple, certain and smooth – and for that reason problems are tabu. We choose to have certainties and no doubts – results and no experiments – without even seeing that certainties can arise only through doubt, and results through experiment. The artful denial of a problem will not produce conviction; on the contrary, a wider and higher consciousness is called for to give us the certainty and clarity we need (p. 99).

3.4. ANALYTICAL PSYCHOLOGY – THE WORK OF CARL JUNG

3.4.1. Introduction

The paradigm analytical psychology focuses on the work of Carl Jung, who is considered the founder of analytical psychology. Jung's work spanned his entire life and his writing was prolific, hence what follows is a brief outline of his theories that pertain to the current study. Despite the fact that Jung's theories were based on his work with psychotic, borderline and neurotic patients as well as his own inner life and self-analysis, "his theories evolved into a description of normal personality more than psychopathology" (Mattoon, 1981, p.1).

3.4.2. Motivation for the use of Jung's theory in this study

Originally a student of Freud's, Jung's original contributions stemmed more from where his views diverged from Freud's. While Freud's unconscious was composed entirely of contents acquired from an individual's experience (personal content), Jung's view of the unconscious was composed partly of personal contents as well as archetypal contents generated outside the realm of the individual's experiences. While Freud's unconscious "was equated with pathology; to Jung it contained healthy, even creative resources as well as some pathological contents" (Mattoon, 1981, p.11). This focus on health and creativity complements the focus of the present study.

Jung's theory is concerned more with experiences, rather than assumptions regarding inner dynamics (Mattoon, 1981), which suits the qualitative nature of this study. In other words, although certain assumptions are made about the human psyche, it is a theory that values subjective experience. According to Jung (in Fordham, 1953) inner or psychic processes have a value equal to the outer or environmental 'reality'. Jung's approach to the understanding of human experience is a respectful one that values the complexity of human relationships, appreciates the influence of culture, and is aware of its own

assumptions. Jung does not present himself as the expert but rather views his own theories as 'suggestions and attempts at the formulation of a new scientific experience with human beings" (Fordham, 1953, p. 15). This tentativeness and openness to other ways of thinking suit the qualitative nature of the study. According to Wilhelm and Jung (in Jung, 1933): "Science is the best tool of the Western mind and with it more doors can be opened than with bare hands"(p. 78), however, "it…only clouds the insight when it lays claim to being the one and only way of comprehending" (p. 79).

Jung's theory has a "quality of 'holism' – based on the assumption that the whole person is more than a combination of elements, such as perceptions – and should be treated as a totality" (Mattoon, 1981, p.16) and suggests a link between 'wholeness' and health. This 'holistic' perspective allows for the integration of other paradigms – a secondary aim of this study. Also, Jung's focus was on adult development throughout life and the fact that this study focuses on the experience of adult women makes Jung's theory more relevant.

3.4.3. Jung's view of personality development

Jung's theory is considered one of the most unusual perspectives in Western psychology (Compton, 2005). Jung's move away from Freud's instinctual drives toward a concept of 'psychic energy' as the driving force in humans was based on "the principle of opposites. Just as in the physical parallel, a flow of energy is produced by the difference in potential between poles" (Mattoon, 1981, p.108). Thus, without opposite poles there can be no equilibrating process – which is energy. Rothenburg (in Mattoon, 1981) explored this phenomenon independently of Jung, stating that there has to be tension between two opposites for creative achievement to occur.

According to Jung (in Mattoon, 1981) the opposite of a flow of energy is entropy, which is a static condition when there is no difference in potential and, hence, no psychic energy – a state that occurs in physical and psychic death. "A condition of perfect harmony is … static. Thus, a mature personality, in Jung's view, is one that is in the process of

development, not one that is in perfect balance" (Mattoon, 1981, p.108). This emphasis on a continual process of development highlights Jung's view that development of the mind is lifelong (Mattoon, 1981, p.11).

While Freud focused on human development from birth to adolescence, Jung tended to focus on development in 'middle life' and 'old age'. This can be seen in Erikson's (1980) stages of development – the first five paralleling Freud's psychosexual stages and the last three matching Jung's stages of development. Jung's three stages of development include: learning about a particular society and how to live in it; establishing oneself in that particular society through work and personal relations, especially marriage; and the age of acquiring wisdom. These stages will be discussed in more detail later in this section. This 'move toward wholeness' described by Jung throughout his work is encompassed in his views on individuation. In fact, his entire theory is sometimes even regarded as one of individuation (Mattoon, 1981). His view that the developmental process is lifelong and:

> …merges, especially in the second half of life, with the individuation process. Individuation leads, by definition, toward wholeness – completeness and undividedness – of personality by integrating the conscious and unconscious parts of the personality. Individuation leads also to uniqueness, which results from differentiating oneself fully from other persons (Mattoon, 1981, p.179).

Hence, Jung's (1979) theory of personality development is linked to the process of individuation and can be said to involve the integration of various opposing aspects of the personality toward a sense of wholeness. This process entails a sense of increasing differentiation of the self from others, however, it must be kept in mind that Jung's theory is one of polarities and while individuation is the goal, it is never fully achieved because individuals are also always bound to the larger community of humanity through the collective unconscious and the archetypes they carry within as an eternal presence

(Jacobi, 1942). This process will be discussed in more detail under the section on Jung's (1933) individuation process.

3.4.4. Jungian theory and the African world view

According to Feldman (2004) Freud was influenced by the colonial viewpoints of the time and equated analysis with the analyst being the 'conquistador' whose aim was to assist the analysand to conquer the dark forces of the unconscious. Jung also "still privileged Western culture and spoke with traces of Eurocentric colonial superiority of the less-evolved 'primitive cultures" (Feldman, 2004, p. 28), however, Jung, "less the conquistador than Freud, spoke of engaging the unconscious in a healing dialogue for the purpose of integration and individuation" (Feldman, 2004, p. 28). Hence, it is important to view Jung's theory from within the colonial context in which it was conceived and note that many post-Jungian scholars have managed to successfully use Jung's theory while viewing other cultures "without judgement or pre-existing categories (Feldman, 2004, p. 28). In fact, it has been shown that Jung's ideas around the self, the stages of life and the collective unconscious actually resonate with traditional African views (Feldman, 2004).

The first way that Jung's theory attempts to embrace culture is his notion of the collective unconscious, which he saw as being a consciousness shared by all humans. His 'collective unconscious' or "objective psyche because it is nonpersonal [has] the power to generate images and concepts, independent of consciousness" (Mattoon, 1981, p.38). These images generated by the collective unconscious were called archetypes. Archetypes are "Jung's term for the content of the collective unconscious" (Drever, 1969) and can be viewed as the shared symbols of the human unconscious. The contents of the collective unconscious are designated 'collective' due to the fact that they are common to all humans and although Jung (1959) recognized that certain archetypes carry a specific cultural meaning, he maintained that there are symbols that carry universal meanings. According to Jacobi (1942) the importance of dreams in certain cultures also

provides a link to the collective unconscious and its symbols. According to Feldman (2004), when studying indigenous cultures, contemporary Jungian analysts look for the "invariant elements, the archetypes of myth [and find that these] myths were created out of a basic (invariant/archetypal) need for order in the human mind…that myths were devised to help resolve conflict between opposites, which is similar to Jung's transcendent function" (p. 28). Jung's (1959) collective unconscious is a controversial concept and according to Battista (1979):

> Much of the controversy concerning Jungian psychology has centred around Jung's hypothesis that the repetitive archetypal images he discovered implied some kind of collective historical unconscious from which these images are inherited. This hypothesis is not supportable in any concrete, physical form and blinded many people to Jung's more basic empirical discovery – that the human psyche is structured in such a way that it is predisposed to mature in a particular manner and to experience the world in a particular way. In this form, Jung's ideas about imagery in relation to the individuation process becomes quite compatible with the structuralist and information-system's approaches of contemporary psychology (Muchielli, 1972; Piaget, 1971; Peterfreund, 1971). That is, what is inherited is not the images themselves, but a structure which predisposes human beings to experiencing particular images. Much of the interest among Jungian analysts today is not trying to verify Jung's hypotheses about the racial inheritance of ideas, but rather to develop an understanding of how the structure of the psyche Jung discovered evolved historically (Battista, 1979).

Another area that Jung's theory resonates with African culture is that his definition of 'Self' is inclusive and overarching, and able to accommodate other ideas of self. Jung (1939) spoke about two concepts of self. While the first self he considered to be the centre of the ego, the other 'Self' he considered to be much larger, incorporating all

aspects of the personality. The Self according to Jung (1939) is considered an archetype, along with the persona, the shadow, the anima and animus, the old wise man and the earth mother. Although there are an infinite number of archetypes, these few were identified by Jung as some of the important ones that influence human thought and behaviour. It is important to note that the archetypes consist of both a collective aspect and a personal aspect, for example, the anima image is based on humanity's age long experience of women and the individual's personal experience with them. According to Fordham (1953): "Some archetypes are, however, more collective than personal, and others, like the persona and the shadow, have a larger personal element" (p. 28). The implication of this statement is that the Self, according to Jung (1939), is both a collective idea and a personal construct i.e. a person's sense of Self incorporates the experience of generations of other Selves as well as his or her own experience of a Self. According to Jung (1939) the experience of the Self is archetypal. Archetypes of the Self are portrayed in dreams and visions in varied images.

According to Jung (1939), the Self emerges from somewhere between the conscious and unconscious and is considered to be the centre of the personality. "The Self is not only the centre, but also the circumference that encloses consciousness and the unconscious; it is the centre of this totality, as the ego is the centre of the consciousness" (Jung, 1939, p. 96). He differentiates it from the self that he considers the ego-centre, which he considers to be the centre of consciousness, stating that if the ego tries to incorporate unconscious elements into itself, it is in danger of destruction, like an overloaded vessel (Fordham, 1953). According to Fordham (1953):

> It [the Self] appears to act as something like a magnet to the disparate elements of the personality and the processes of the unconscious, and is the centre of this totality as the ego is the centre of consciousness, for it is the function that unites all the opposing elements in man and woman, consciousness and unconsciousness, good and bad, male and female…and in doing so transmutes them. To reach it necessitates an acceptance of what is

inferior in one's nature, as well as what is irrational and chaotic…Jung makes it clear that his concept of the [S]self is not that of a kind of universal consciousness, which is really only another name for the unconscious. It consists rather in the awareness on the one hand of our unique natures, and on the other of our intimate relationship with all life…It brings a feeling of 'oneness', and of reconciliation with life, which can now be accepted as it is, not as it ought to be (p. 62-63).

Jung's (1939) description of Self seems closely related to psychological components reflective of an African worldview identified by writers from the African perspective, which are characterized by three concepts: holistic spiritual unity, communalism, and proper consciousness or self-knowledge (Ncgobo, in Eskell-Blokland, 2005). According to Marcus and Kitayama (in Eskell-Blokland, 2005): "Africans…view the world and others as extension of one another. The self is viewed not as a hedged closure but as an open field (p. 125) and according to Ephirim-Donker (in Eskell-Blokland, 2005): "The [African]…sees himself/herself modestly as part of the great stream of life that transcends his/her own self. Hence, Jung's notion of the Self can be said to similar to the African concept of NTU, which is the notion that all beings and things are connected through time and space (Jahn, 1990). Hence it appears that both Jung's conception of Self and the African perspective on self incorporate both a personal and collective aspect and a sense that the self is a transcending function that binds us to all life.

3.4.6. Jung's theory on the individuation process and the stages of life

Jung (1933) saw this process as divided into two main stages. In the first "a conscious ego perspective is separated from the individual's originally unified, but unconscious experience of life" (Battista, 1979, p. 115). In the second stage "the individual ego is consciously reintegrated with this unified state, called the self" (Battista, 1979, p. 115). For this integration to occur, "the aspects of the self which were denied, repressed,

projected or left unexperienced must be confronted and experienced" (Battista, 1979, p. 115).

According to Jung (in Battista, 1979) the infant in utero lives in a "state of undifferentiated unity. There is no separation of inner and outer, subject and object. The infant is complete, yet unconscious of its self…as the infant develops in utero, its increasingly independent biological system separates itself from the mother" (p. 115). The mother's body continues to meet the developing infant's needs, however the unity between them has become less perfect and more of a "dynamic interplay" (Battista, 1979, p. 115). According to Battista (1979) this interplay is "deepened and made more complex by the advent of birth and the physical separation of mother and child" (p. 115). As the mother and child become more separate and independent of each other, the child's needs are inevitably frustrated and it is these experiences that reinforce the child's developing sense of separateness and individuality. Due to the fact that the infant is helpless and if left alone would die, there is a large degree of anxiety evoked in the infant by separation, hence, "the infant is thus gratified to have its needs met and return it to its original state of non-separateness" (Battista, 1979, p. 115). According to Edinger (1973) the interaction between the child and the mother around separation and re-integration becomes an axis around which further differentiation can take place. According to Battista (1979) this dynamic interaction "marks the original separation of ego and self" (p. 115). According to Jung (1933) the first stage of consciousness which we can observe in an infant is when there is connection between two or more psychic contents. Jung (1933) states:

> At this level, consciousness is merely sporadic, being limited to the representation of a few connections, and the content is not remembered later on. It is a fact that in the early years of life there is no continuous memory; at the most there are islands of consciousness which are like single lamps or lighted objects in the far-flung darkness (p. 101).

According to Jung (1933) these islands of memory are not the same as connections between psychic contents; the initial connections made between psychic contents form a series which eventually constitute the ego. The ego becomes an object in consciousness and Jung (1933) explains that this is the reason that the child first speaks of itself in the third person. Only once the ego becomes charged with energy of its own and can be perceived as fully separate does a feeling of 'I-ness' emerge and this is when the child begins to speak of itself in the first person. Jung (1933) regards this as the beginning of continuity of ego-memories. Battista (1979) states: "It is important to understand in this regard that the mother is the child's first conscious experience of the self. The nature of the mother-child interaction thus gives form to the ego's relationship to the self" (p. 115). It is in this area that Jung's (1933) theory of individuation overlaps with that of Winnicott (1960).

According to Battista (1979) the ideal mother provides both gratification and frustration of needs, which encourages individuation. While the aim is to be balanced in frustrating and nurturing qualities, all mothers overgratify or overfrustrate or do a combination of both. Battista (1979) states that this is a result of both the mother's and the child's personality and what their interaction evokes in the two of them. Depending on this interaction, the child's ego and image of the mother become structured in a particular way. According to Battista (1979):

> A permissive mother who loves having a child close to her will evoke a strong positive image of mothers in a child. To compensate for this, unconscious images of a devouring, engulfing mother are constellated because such a mother inhibits a child from fully differentiating its ego. Alternately, a critical mother cripples the child's sense of well-being and gives a negative cast to the ego's images of mother. To compensate for this, images of the great mother, the nurturing Madonna, may be constellated (p. 116).

According to Jung's (1933) process of individuation, after the initial childish stage of consciousness comes puberty, which he called "the unbearable age" (p. 101). As the child moves out into society and learns how to behave in particular ways, due to sex-role adaptation, certain aspects of their sexual expression are not actualised. These aspects then constitute "an unconscious contrasexual complex known as the anima in the male and animus in the female" (Battista, 1977, p. 116). It is also during this stage of individuation that the shadow begins to develop. The shadow is also an unconscious complex that is constituted of all the same-sex characteristics of the self that the socialised child regards as unacceptable (Battista, 1979). It is during this period that the individual experiences what formerly would have been regarded as outer limitations as inner obstacles. Inner tension is experienced as one impulse opposes another, which brings about an estrangement from oneself – which Jung (1933) called an ego-complex. Jung (1933) states:

> …the first stage of consciousness which consists of recognising or 'knowing' is an anarchic or chaotic state. The second – that of the developed ego-complex – is a monarchic or monistic phase. The third is another step forward in consciousness, and consists in the awareness of one's divided state: it is a dualistic phase (p. 102).

It is at this point that Jung (1933) begins his theory on the stages of life. The first stage is from roughly the first years after adolescence into mid-life (35 – 40). It is during this time that the child is transformed into an adult through separation from their family as an independent person. "This process generally involves accepting some social role or collective identity which both expresses and defends the person in his new independent position. This defensive, yet adaptive, role of the individual is called their persona" (Battista, 1979, p. 116). The persona develops as the person learns how to live in the world and establishes him/herself in society through work and family. According to Jung (1933): "Of course, to win for oneself a place in society and so to transform one's nature that it is more or less fitted to this existence, is in every instance an important achievement" (p. 106). However, once this has been achieved i.e. the persona has been

established and the individual ego has become consciously separated from its self by identifying with a collective or social role, the first stage of the individuation process is complete. There is then a gradual movement into the second stage of individuation. According to Jung (1933):

> The nearer we approach to the middle of life, and the better we have succeeded in entrenching ourselves in our personal standpoint and social positions, the more it appears as if we had discovered the right course and the right ideals and principles of behaviour. For this reason we suppose them to be eternally valid, and make a virtue of unchangeably clinging to them. We wholly overlook the essential fact that the achievements which society rewards are won at the cost of diminution of personality. Many – far too many – aspects of life which should also have been experienced lie in the lumber-room among dusty memories. Sometimes, even, they are the glowing coals under grey ashes (p. 106).

In the second stage of individuation the process reverses. According to Battista (1979): "It is as if the individual's assertion of itself as a fully conscious, independent person motivated solely by its own wishes, wants and desires activates the compensating images of the second movement of the individuation process" (p. 116). During this stage of individuation the aspects of the self that were sacrificed in order to establish a social identity need to be confronted and integrated. Unconscious complexes play an important role in this reintegration process (Battista, 1979). Although this stage of individuation tends to take place in the second half of life, after the so-called mid-life crisis, many people can become involved in this process at an earlier stage (Battista, 1979). This stage involves confronting one's persona or adaptation to life and becoming ready to give up one's protection and relate more as him/herself. "When this confrontation is successful, these persons will feel more natural in their social functioning" (Battista, 1979, p. 117).

This stage also entails confronting the shadow or rejected, unconscious aspects of the self. The process of confronting these aspects of the self which have been spilt off and rejected from consciousness is often facilitated by realising that these aspects are often projected onto people or institutions around one. "In order to integrate these bad or negative aspects of one's self, individuals must learn to see their positive side, how they are perversions of a positive strength that the person is in need of, or come to understand that they are rooted in some fear of proceeding further in their self-confrontation" (Battista, 1979, p. 118). Jung (1933) explains this process through an example of a church warden he knew:

> I know of a pious man who was a churchwarden and who, from the age of forty onward, showed a growing and finally unbearable intolerance in things of morality and religion. At the same time his disposition grew visibly worse. At last he was nothing more than a lowering 'pillar of the church'. In this way he got along until his fifty-fifth year when suddenly, one night, sitting up in bed, he said to his wife: "Now at last I've got it! As a matter of fact I'm just a plain rascal." Nor did this self-realisation remain without good results. He spent his declining years in riotous living and in wasting a goodly part of his fortune. Obviously quite a likeable person, capable of both extremes! (p. 108).

Jung's emphasis on heightening the awareness of our own personal 'shadow' or darkness can help us understand others' shadows, which can prevent the 'we-they' mentalities that can produce hostile and punitive attitudes toward people outside a person's own social group. Considering the stigma and fear surrounding HIV/AIDS and the consequences of this stigma for people with the disease, this is a relevant concept.

The third part of this second stage of individuation involves confronting the contrasexual elements of one's self i.e. the anima or animus. According to Battista (1979): "These complexes [anima and animus] are more unconscious than the shadow because they

represent latent or unrealised aspects of the person which have never been conscious rather than elements which were rejected or repressed from consciousness" (p. 118). According to Jung (in Battista, 1979) most people's first experience of the anima or animus is falling in love, where their anima or animus is projected onto their lover. Over time, as the lover does not meet the archetypal expectations that were projected onto them, in order to love the actual human being of the lover, the person must confront their own anima/animus projections. "Thus, anima and animus figures not only confront individuals with how they relate to the opposite sex, but impel them to confront those aspects of contrasexuality of which they are unaware" (Battista, 1979, p. 119). Jung (1933) states that in the second half of life during the second stage of his theory of individuation, men and women are confronted with their anima and animus through aging:

> But there is something sunlike within us; and to speak of the morning and spring, of the evening and autumn of life is not mere sentimental jargon. We thus give expression to the psychological truth, even more, to physiological facts; for the reversal at noon changes even bodily characteristics (p. 109).

Jung (1933) speaks of an example of this in ethnological literature:

> …an Indian warrior-chief to whom in middle age the Great Spirit appeared in a dream. The spirit announced to him that from then on he must sit among the women and the children, wear women's clothes and eat the food of women. He obeyed the dream without suffering any loss of prestige. This vision is a true expression of the psychic revolution of life's noon – of the beginning of life's decline. Man's values and even his body tend to undergo a reversal into the opposite (p. 110).

According to Jung (1933), the process of confronting the anima or animus is about discovering and integrating characteristics of the opposite sex that were formerly repressed and he speaks of the transformation with age as weighing "more heavily still in the psychic realm than in the physical" (p. 110). He states:

> …one sees that the thing which has broken down is the masculine style of life which had held the field up to now; what is left over is an effeminate man. Contrariwise, one can observe women in these self-same business spheres who have developed in the second half of life an uncommon masculinity and an incisiveness which push the feelings and the heart aside (p. 110).

Jung (1933) speaks of the need to embrace these opposite qualities and incorporate them into the personality in order to move towards a new sense of wholeness. He feels that as a species we would not grow to be old if there was no meaning or significance in growing older:

> …the afternoon of human life must also have a significance of its own and cannot be merely a pitiful appendage to life's morning. The significance of morning is undoubtedly lies in the development of the individual, the propagation of our kind and the care of our children. This is the obvious purpose of nature. But when this purpose has been attained – and even more than attained – shall the earning of money, the extension of conquests and the expansion of life go steadily beyond the bounds of all reason and sense? Whoever carries over into the afternoon the law of the morning – that is, the aims of nature – must pay for doing so with damage to his soul…For the most part our old people try to compete with the young. In the United States it is almost an ideal for the father to be the brother of his sons, and for the mother if possible to be the younger sister of her daughter… (p. 112).

According to Jung (1933) for many people it is difficult to see what value lies in the second half of life. For many the second half of life offers only a diminution of life. He explains that this is often due to people not having lived to the fullest in the first half. Jung (1933) believed that the purpose of the second half of life is to individuate further. While the first half of life holds the challenge of individuating from family and becoming an independent person in society, the second half involves individuating from this sense of individualism and moving toward a larger sense of collective meaning. This he felt could be achieved through confrontation with the Self. Once a person has confronted and integrated the persona, shadow and anima or animus, the various parts of the personality have been realised. The final part of this second stage of individuation is then for the individual to confront the Self, which is an aspect of psychological life that according to Battista (1979) "transcends any individual differentiation or limitation" (p. 119). Battista states: "This confrontation of ego with the [S]self marks the final, deepest and most intriguing aspect of the individuation process. The ego must consciously realise the wholeness of the [S]self, yet in order to do so, it must give up its sense of importance and control" (p. 119). Referring to the experience of the Self, Wilhelm and Jung (in Jung, 1933) state: "It is as if the leadership of the affairs of life had gone over to an invisible centre…and there is a release from compulsion and impossible responsibility which are the inevitable results of *participation mystique*" (p. 78-79).

Jung (1933) describes how it is the task of the second half of life to find meaning and share wisdom. He speaks about how Western cultures have lost this significance of old age:

> Moneymaking, social existence, family and posterity are nothing but plain nature – not culture. Culture lies beyond the purpose of nature. Could by any chance culture be the meaning and purpose of the second half of life? In primitive tribes we observe that the old people are almost always the guardians of the mysteries and the laws, and it is in these that the cultural heritage of the tribe is

expressed. How does the matter stand with us? Where is the wisdom of our old people – where are their precious secrets and their visions? (p. 112).

Hence, Jung's (1933) theory of individuation can be said to be a series of separations but also reunions. In the first stage of Jung's (1933) individuation process the focus is on the infant's initial separation (Bowlby, 1980; Winnicott, 1960). From the union with mother that is being carried in the womb, the separation being birth, to the separation from mother that occurs with the development of a separate ego and consciousness and the realisation that he or she, the infant, and mother are separate individuals. Jung describes childhood up until puberty as being a time when consciousness has developed but a time also when the child has not yet encountered any real inner conflicts. This would be disputed by the object relations and attachment theorists, who propose that the child experiences a great deal of inner conflict, the resolution of which often entails the development of psychological defences to a lesser or greater degree. It seems though that as Jung broke away from Freud, he focused more on adulthood, and left Freud to focus on the child up until puberty with his psychosexual stages of development.

The second stage that Jung (1933) describes happens from puberty, through adolescence and young adulthood to middle age. He describes this stage as when the individual breaks away from his or her family and establishes his or her own place in society – in an attempt to conform and belong. It entails the development of the persona, anima or animus and the shadow. Thus, while it is a separation from family, it is a union with society.

The third stage of individuation described by Jung (1933) is after middle age and into old age. He describes this as a time of individuating away from the norms of society and a time of confrontation with one's persona, shadow, anima or animus and eventually, one's Self. Hence, while there is a separation from society there is a move toward the Self. It is important to note that Jung's concept of Self incorporates a much wider sense of community in that he viewed the Self as connected to all that exists.

Thus, it can be seen that Jung's (1933) ideas around individuation encompass his ideas around integrating both polarities. The paradox he presents is that although life appears to entail a series of separations, each time one inevitably becomes more connected on a different level. It was in fact exploration of other cultures that first led Jung to formulate his concept of individuation. His study of Chinese culture and philosophy in particular led him to write 'The Secret of the Golden Flower' with sinologist Richard Wilhelm. The book explores the similarities of an ancient Chinese mysticism and the experiences of patients on the path to individuation. The secret of the Golden Flower:

> …is built on the premise that cosmos and man in the last analysis obey common laws; that man is a cosmos in a miniature and is not divided from the great cosmos by any fixed limits. The same laws rule for the one as for the other and from the one a way leads into the other. The psyche and the cosmos are related to each other like the inner and outer worlds. Therefore man participates by nature in all cosmic events, and is inwardly as well as outwardly interwoven with them. Tao, then, the meaning of the world, the way, dominates man just as it does invisible and visible nature (Heaven and Earth)… Tao the undivided, Great One, gives rise to two opposite reality principles, Darkness and Light, Yin and Yang (Wilhelm & Jung, in Jung, 1933, p. 11).

According to Fordham (1953) it is the reconciliation of the opposites that constitutes 'Golden Flower' meditation or Jungian individuation. Although Jung (1933) gave no definitive opinion on the matter, his theories on religion and life after death imply that he may have considered death to be merely another transition, rebirth or individuation – although this time from earthly life into another form of spiritual life. The final stage of individuation, according to Jung (1933) is the confrontation with death. According to Jung (1933) death is the great perfector who draws an inorexable line under the balance sheet of human life. In death alone is wholeness – one way or another – attained. While

death is the end of empirical man, it is the goal of the spiritual man. According to Jung death becomes the goal of life and not just its conclusion and it represents a state of rest and wholeness.

3.4.7. Jungian individuation as the Hero's Journey

Jung's (1933) process of individuation or of consciously realising the wholeness of the Self has been called the sublimation of the ego to the Self (Neumann, 1970) as well as the Hero's Journey. Campbell (1972) wrote about the common theme of discovering the Self through confrontation with aspects of the personality which is found in myths from all around the world. Often in mythology the metaphor of the cripple is used to symbolically represent those in psychological crisis. Often broken in spirit or on their knees, they are unable to function in their usual ways. However, paradoxically, being crippled, blind or otherwise disabled in mythology is also associated with wisdom. These people are often heroes who have conquered some insurmountable suffering (Sharp, 1998). The hero is usually associated with an unusual fate where his task is to do something out of the ordinary. The goal of the journey is to survive a dangerous ordeal "to find the treasure, the ring, the golden egg, the elixir of life – psychologically, these all come to the same thing: oneself – one's true feelings and unique potential" (Sharp, 1998, p. 108). According to Jung (in Sharp, 1998) this journey is analogous to the psychological "attempt to free ego-consciousness from the deadly grip of the unconscious" (p. 110). "In the language of the mystics it is called the dark night of the soul" (Sharp, 1998, p. 110). This experience usually entails feelings of despair, loneliness and a desire to escape or hide.

Campbell (1972) studied the patterns of themes in mythology across time and cultures and identified the theme of a journey, which he termed 'The Hero's Journey'. Within this journey there are three stages: Separation, Initiation and Return. Separation entails the protagonist receiving the 'call to adventure' upon which he/she begins to move from the world he/she knows to the unfamiliar or unknown. Initiation is where the hero enters

the unknown, the world of the supernatural where he/she meets demons and dragons and must survive a series of tests with newly acquired powers. Return is where the hero has survived and must now return to the world he/she knew before, relinquishing his/her powers but keeping some new qualities, with which things are set in order (Lukoff, 1985). In other words, the journey entails the overcoming of a struggle and the subsequent integration of the new information gained from it into their old framework. This process is also described by Battista (1979):

> Initially, the hero or heroine may be tested by a number of trials. Although individuals may first be called upon to prove their courage by slaying various beasts and performing difficult tasks, eventually they are called to submit themselves to that which is greater than they are, the Self. The most frequent difficulties involve the ego's attempt to possess the Self and thus maintain its control. This result is an inflation or aggrandizement of the ego (Edinger, 1973). Instead, the individual must submit to the Self, to be contained by it, and thus transformed… (p. 120).

Thus transformed after the Hero's Journey, it is considered the task of the individual to bring this new found wisdom back home, thereby completing the cycle. Campbell's 'Hero's Journey' explains the relevance of myth to mental illness or psychological suffering. The battles and ordeals of princes and dragons are a metaphor for the venture into the psyche and thus are helpful in understanding the process of mental illness or psychological distress (Lukoff, 1985). Campbell (1972) believed that mystics, yogis and individuals in psychological distress are "all plunged into the same deep inward sea" (Lukoff, 1985, p. 3). However, Campbell (1972) states: "The mystic, endowed with native talents for this sort of thing and following stage by stage, the instruction of a master, enters the waters and finds he can swim: whereas the schizophrenic, unprepared, unguided, and ungifted, has fallen or has intentionally plunged, and is drowning" (p. 216).

3.4.8. Jung's view of God and religion

Jung (1938) defined religion as an:

> …attitude of the human mind, which could be formulated in accordance with the original use of the term 'religio', that is a careful consideration and observation of the certain dynamic factors, understood to be 'powers', spirits, demons, gods, laws, ideals, or whatever name man has given to such factors as he has found in his world, powerful, dangerous, or helpful enough to be taken into careful consideration, or grand, beautiful, and meaningful enough to be devoutly adored and loved (p. 5).

According to Fordham (1953) the key concept in Jung's definition of religion is the word 'dynamic'. Fordham (1953) stated that the dynamism of religion is the energy of the religious function that caused crusades and witchhunts, that still causes religious wars, and that fuels the creative efforts of art and buildings in which to worship and adore. Jung's views allow for an alternative interpretation of spirituality and religion as, unlike other psychodynamic theories, that regard religion as an illusion or projection, Jung's theory makes space for spirituality and religion. Jung states that humans possess what he calls a 'natural religious function' and that mental health and stability depend on proper expression of this function (Fordham, 1953). Jung (1938) believed that religion and spirituality are linked to the innate human needs to find meaning in life, connect to something bigger than the self, and to experience wholeness or a sense of completeness. Fordham (1953) states:

> This [Jung's 'natural religious function'] is in direct contrast to those who view religion as an illusion, an escape from reality, or a childish weakness. So widespread has this attitude become, even if not consciously realized, that we have almost lost sight of the important part that religion has played in our history, the intensity of emotion it

aroused, and the tremendous energy it canalised into the arts, into the creation of fine buildings, into learning, teaching and caring for the weak, the sick, and the poor. The lovely cathedrals and the large churches which adorn even tiny villages are standing evidence of its past influences, just as priests' hiding-holes and Huguenot surnames are reminders of more sinister aspects of the religious spirit, its fanaticism and its cruel energy in persecuting all those who did not see eye to eye with it (p. 69).

Jung's (1933) ideas around man's 'natural religious function' were based on his observations that people have access to symbols and images from the collective unconscious that include the idea of life after death:

We only understand that thinking is a mere equation, and from which nothing comes out but what we have put in. That is the working of the intellect. But beyond that there is a thinking in primordial images – in symbols which are older than historical man; which have been ingrained in him from earliest times, and, eternally living, outlasting all generations, still make up the groundwork of the human psyche. It is only possible to live the fullest life when we are in harmony with these symbols; wisdom is a return to them. It is neither a question of belief nor of knowledge, but of the agreement of our thinking with the primordial images of the unconscious. They are the source of all our conscious thoughts, and one of these primordial thoughts is the idea of life after death…Before the nineteenth century the thyroid was regarded as a meaningless organ, merely because it was not understood. It would be equally short-sighted of us today to call these primordial images senseless. For me these images are something like psychic organs, and I treat them with the very greatest care. It happens sometimes that I must say to an older patient: 'Your picture of God or your idea of immortality is

atrophied; consequently your psychic metabolism is out of gear."

The ancient *athanasias pharmakon,* the medicament of immortality,

is more profound and meaningful then we supposed (p. 116).

Hence, Jung (1933) believed that through a deeper level of unconscious processing, access is gained to a sense of spirituality. When access is gained to certain archetypes in the collective unconscious the need for spirituality is felt and the motivation to pursue this need is found. The archetypes to which Jung (1933) refers could be viewed as representing universal emotional and psychological impulses that underlie the human quest for spirituality, regardless of culture. Jung (1933) viewed religion as being schools for people in the second half of their lives and believed that the fact that all the great religions of the world offer a promise of life after death is what makes it possible for people to live the second half of their lives with as much perseverance and determination as the first half. Although acutely aware of the fact that life after death cannot be known, as a physician he stated:

> I have observed that a directed life is in general better, richer and healthier than an aimless one, and that it is better to forwards with the stream of time than backwards against it…as a physician, I am convinced that it is hygienic – if I may use the word – to discover in death a goal towards which one can strive; and that shrinking away from it is something unhealthy and abnormal which robs the second half of life of its purpose. I therefore consider the religious teaching of a life hereafter consonant with the standpoint of psychic hygiene…from the standpoint of psychotherapy it would therefore be desirable to think of death as only a transition – one part of a life-process whose extent and duration escape our knowledge…a large majority of people have from time immemorial felt the need of believing in a continuance of life. The demands of therapy, therefore, do not lead us into any bypaths, but down the middle of the roadway trodden by humankind. And therefore we are thinking

correctly with respect to the meaning of life, even though we do not understand what we think (p. 115).

Jung's (1933) rationale behind his controversial statements seems to be based on the practicalities of what he observed in his patients. Rather than try to prove the existence of life beyond death, he merely accepted it as an unknown or matter of faith and chose rather to look at the value belief can offer:

> For, in what follows, I shall look at the venerable objects of religious belief. Whoever talks of such matter inevitably runs the risk of being torn to pieces by the two parties who are in mortal conflict about those very things. This conflict is due to the strange supposition that a thing is true only if it presents itself as a physical fact. Thus, some people believe it to be physically true that Christ was born as the son of a virgin, while others deny this as a physical impossibility. Everyone can see that there is no logical solution to this conflict and that one would do better than to get involved in such sterile disputes. Both are right and both are wrong. Yet they could both reach agreement if only they dropped the word 'physical'. 'Physical' is not the only criterion of truth: there are also *psychic* truths which can neither be explained nor proved nor contested in any physical way…After all, we can imagine God as an eternally flowing current of vital energy that endlessly changes shape just as easily as we can imagine him as an eternally unmoved, unchangeable essence. Our reason is sure only of one thing: that it manipulates images and ideas which are dependent on human imagination and its temporal and local conditions, and which have changed innumerable times in the course of their long history. There is no doubt that there is something behind these images that transcends consciousness and operates in such a way that the statements do not vary limitlessly

and chaotically, but clearly all relate to a few basic principles or archetypes. These, like the psyche itself, or like matter, are unknowable as such. All we can do is construct models of them which we know to be inadequate…If, therefore, in what follows I concern myself with these metaphysical objects, I am quite conscious that I am moving in a world of images and that none of my reflections touches the essence of the Unknowable (p. xi – xiii).

Jung (1933) believed that spirituality is far too complex to be captured by language and it was for this reason that he felt religious experience was best captured by images, symbols and rituals. It is through these that people are able to connect to collective unconscious experience.

3.4.9. Jung's view of 'Rebirth'

Jung's idea of rebirth is discussed in his works, 'Psychology and Alchemy' and 'The Psychology of Transference'. In these works Jung suggests that images of incest, death and decay are essential preludes to the whole-making process (Plaut, 1984). In other words, crisis or hardship is often required for the growth process to occur. According to Plaut (1984):

Perhaps 'crisis' would do to express an important turning point in a person's life. But then that would impoverish the event of all that led up to it and what came out of it and above all, it would lose the characteristics of the person to whom it seemingly had to happen when it did. What is more, crisis orientates one towards contingency planning and problem solving rather than towards the feeling of having undergone a lucky or even miraculous transformation of death, recovery and renewal. At

any rate…inevitably painful separations tend to precede a creative breakthrough (p. 9).

Jung's (1959) concept of rebirth was developed out of an experience he had that involved his own near-death. In 1944 Jung broke his foot and shortly after this suffered a heart-attack. Of this event, Plaut (1984) wrote:

> In a state of unconsciousness, he experienced visions and hallucinations. These, combined with the medication he received, made him conclude that he was close to death…Jung at that time had a series of visions…accompanied by a feeling of detachment. He felt weightless and floating in space; at least three weeks passed before he could truly make up his mind to live again (p. 9).

In his biography, Memories, Dreams and Reflections, Jung (1963) wrote about this experience stating that he experienced a vision of the end of all things and these new insights gave him the courage to undertake new formulations. Plaut (1984) describes Jung's concept of rebirth as being a multitude of psychodynamic processes. He explains that the terms self-realization, integration, healing, whole-making and individuation all refer to Jung's concept of rebirth. Plaut (1984) states that rebirth has many meanings, such as: "transmigration of souls, reincarnation, resurrection and participation in rituals such as in initiation and healing through birth ceremonies" (p. 10). Jung (1959) called rebirth that occurs within an individual human life 'renovatio', stating:

> This word has a special flavour; its whole atmosphere suggests the idea of renovation, renewal, or even of improvement brought about by magical means. Rebirth may be a renewal without any change in being, inasmuch as the personality which is renewed is not changed in its essential nature, but only its functions, or parts

of the personality, are subjected to healing, strengthening, or improvement (Jung, 1959, p. 114).

According to Plaut (1984), Jung's concept of rebirth is about change and he warns of "dangers which surround every change and transformation whether it concerns an individual or large social groups" (p.10). These dangers, according to Jung (in Plaut, 1984) are: in the language of primitive psychology 'loss of soul', lethargy and depression, disturbed sleep and anxious resistance to change. Ironically though, "life may depend on giving up so-called security" (Plaut, 1984, p. 10). Plaut (1984) speaks about syntheses of various kinds resulting in rebirth. He explains the "powerful and unforeseeable effect which approaching death can have – be it one's own or that of somebody close to the dying person. Regeneration of oneself in these circumstances can be so marked, if mysterious…" (p. 14).

Rebirth according to Jung is connected to the losing and finding of oneself and the need for synthesis between divisions in the personality (Plaut, 1984). Jung equates the Freudian superego with a collective moral conscience or code and viewed the self as an inner authority free from conventional morality. The battle between these two requires an ego that is capable of separation, just as rebirth requires for there to have been a previous birth. This ego allows for choice and "further developments involving separation and becoming an individual" (Plaut, 1984, p. 18).

3.4.10. Conclusion

Eskell-Blokland (2005) writes that while psychological theories based on Euro-American values typically involve:

>…self-realization, the building of ego strength and boundaries, personal achievement and individualism, independence and the successful leaving of the parental home…according to scholars writing from an Afrocentric

perspective, values of traditional African cultures influencing the concept of the self within those cultures, are characterised by communalism or collectivism, dependency or interdependency, non-competitiveness and successful assimilation into the community (p. 124)

Jung's theory seems to encompass both individualism and collectivism, dependency and independency, individuation and assimilation. Jung seems to have an appreciation for all of that which constitutes human experience. Writing on Jung's opinion on the study of human experience, Fordham (1953) states:

> There is no simple formula to which this [human] experience can be reduced; to focus on one point leads to a gain in clarity, but the network of relationships in which psychic activity consists is lost sight of. The search for precision in defining mental experience robs it of much that by nature belongs to it (p. 15).

Thus it can be seen that the aspects of Jung's theory discussed above tend to encompass a wide range of human experience. The themes covered in this section, namely: death-rebirth, individuation, shame, religion and dependence – all emerged from the data and will be discussed in relation to the study findings in chapter seven.

3.5. CRITICAL DISCUSSION AND INTEGRATION OF THEORETICAL APPROACHES

3.5.1. Difficulties associated with studying the experience of people from an African culture from a Western perspective

3.5.1.1. Introduction

When using Western theories to describe African experience, an obvious tension is set up. It may be argued that it is an attempt to force African worldviews to conform with Western ways of thinking or Western knowledge, however this is not the intention of this study. This study aims to respect both traditions and integrate them in a manner hopefully acceptable to both African and Western perspectives. In order to understand more clearly how this may be achieved, a brief critical discussion on 'cross-cultural' psychology and the interplay between African and Western approaches to knowledge is necessary. With particular reference to this section, a social constructionist perspective needs consideration with regards to the role it plays in its critical questioning of the theories that developed in the modern era, and its emphasis on the importance of culture in understanding.

3.5.1.2. Cross-cultural psychology

Western psychology's struggle with the mind-body split, or the natural science versus social science debate, has been echoed in psychology's exploration of culture. In the early decades of the 20th Century, interest in cultural context diminished as "with the hegemony of logical empiricist metatheory and behaviourist theory the discipline became increasingly enamoured with the possibility of general laws or principles – transcultural and transhistorical" (Gergen & Gergen, 2003). However, this universalizing orientation resulted in 'cross-cultural' psychology in which the majority of research has attempted to

show that certain psychological processes are common across culture or that some psychological processes show cultural variations (Gergen & Gergen, 2003).

One of the most serious criticisms leveled against psychology as a whole has been its attempts to be classed as a science and gain credibility in terms of the medical model. According to Held (2004) with regards to medicine and physical health what is classed as good and bad is fairly straightforward, that is, if it eases physical distress and helps you to live longer it is good, if it causes physical distress and shortens your life, it is bad. However, in psychology, what is good and bad is not so simple. According to Norem (2001) a 'one size fits all' model in terms of psychology does not work. Gable and Haidt (2005) state: "…the meaning of what is positive or good is complex and multidimensional, and the study of…psychological topics requires recognition of this complexity in theories and empirical designs" (p. 108).

According to Compton (2005) "…psychology has often neglected the impact of broad social contexts on behaviour. Too often, this results in definitive statements being made about "human behaviour" that actually apply only to people living in specific cultural situations" (p. 239). Although this cross-cultural psychological approach is still present, according to Gergen and Gergen (2003):

> Owing possibly to processes of enhanced global consciousness and multi-cultural appreciation, a more dramatic adventure into the cultural arena has emerged within recent years. This movement toward a cultural psychology has not yet acquired paradigmatic coherence, but its principle drama derives from elevating the status of cultural influences over that of psychological process. That is, where cross-cultural psychology has generally presumed universal psychological process – viewing culture simply as a site for variation – cultural psychology tends to hold culture as the birthing site for psychological processes. The universal in psychology is replaced with the indigenous (p. 1)

3.5.1.3. Move toward a more culturally sensitive psychology

Within the postmodern paradigm, social constructionism in particular has increased awareness of the role that society, culture and language play in creating our beliefs and highlighted the fact that meanings are not universal (Gergen & Gergen, 2003). According to Barnouw (in Compton, 2005) culture can be defined as "the set of attitudes, values, beliefs and behaviours shared by a group of people, communicated from one generation to the next via language or some other means of communication" (p.233). Studies have shown that that culture and social context play a large role in how people perceive themselves, their relationships, their responsibilities and their world. Bruner (in Gergen & Gergen, 2003) states that cultural beliefs are not a set of self-assuaging illusions, but rather working hypotheses about what makes it possible for people to live together in a fulfilling manner, and therefore need to be considered when trying to understand psychological processes.

Most of the research done regarding the differences between cultures has centred around the differences between individualistic and collective cultures. Most Western cultures are classed individualistic and can be described as tending:

> …to place greater emphasis on individualism, autonomy, freedom of expression, and on each person's internal thoughts, emotions and experiences. These societies place a greater emphasis on self-sufficiency or self-reliance, expressing oneself, and on "actualizing the inner self". Individualistic cultures tend to highlight socially disengaged emotions or emotions that encourage independence of the self, such as self-satisfaction or self-righteous anger (Compton, 2005, p. 238).

Cultures like Chinese, Japanese and African tend to be classed as collective cultures and they are described as tending:

…to be more socially oriented and place emphasis on a person's immediate group and on the significant relationships between the members of the group. In general, a greater emphasis is placed on the welfare of the person's extended family; the individual's needs and desires are secondary to those of the group. Autonomy and independence are often de-emphasized in order to focus on the welfare of the group. Feelings of self-worth in collectivist societies may depend on how well a person can respect authority and fit in with his or her important and significant relationships… This is particularly true for women in collectivist cultures… Collectivist cultures tend to emphasize socially engaged emotions or those that highlight communal relationships such as humility or indebtedness (Compton, 2005, p. 238).

However, as noted previously in the literature review on African conceptualizations of self, recent writers in African studies have begun to object to the notion of African cultures as collectivist and to "characterizations of an African self that imply the collectivist variety of interdependence" (Adams & Dzokoto, 2003, p. 347) as this implies loss of personal identity in the collective and a case of Western 'othering' (Shaw, 2000). According to Adams and Dzokoto (2003) considering African cultures as collective seems to be "more a projection of Western categories than a reflection of the constructions of self that prevail in African settings" (p. 347). This needs to held in mind while studies on 'collectivist' cultures are discussed.

With regard to emotion, differences seem to have been found in how various cultures define, label, express and give meaning to emotion (Matsuomoto, in Compton, 2005). Whereas individualistic cultures tend to regard emotions as being inner, subjective experiences, collective cultures tend to view emotions as social constructions i.e. shared experiences created by people and their environments. The expression of emotion is

regulated by cultural display rules, which are the rules that certain cultures hold regarding the appropriate expression of various emotions in public (Compton, 2005).

Another important consideration when exploring the differences between individualistic and collective cultures is the concept of self. According to Compton (2005):

> Obviously, when we define the self, or who we are inside, we simultaneously define what aspects of the world will not be part of our self-identity. In fact, cultures differ in how they define the boundaries of self-identity. In turn, this boundary of self is related to how we define roles, expectations, and responsibilities for ourselves and others (p. 237).

One of the major criticisms leveled against psychology as a whole is that the focus of most theories developed in the past century has been on the individual. According to Seligman and Csikszentmihalyi (2000): "In some of its incarnations, it [traditional psychological theory] emphasized the self and encouraged a self-centeredness that played down concerns for collective well-being" (p. 7). According to Compton (2005):

> Both Sigmund Freud and the early behaviourists believed that humans were motivated primarily by selfish drives. From that perspective, social interaction was possible only by exerting control over those baser emotions. Therefore, people were always vulnerable to eruptions of violence, greed, and selfishness. The fact that humans actually lived together in social groups was seen as a tenuous arrangement that was always just one step away from violence (p. 7).

Hence, when using Western theories to understand the experience of a person from a collective culture, it is extremely important to bear in mind the differences and the

implications these differences may have for the interpretation of certain statements and behaviours. According to Compton (2005):

> People in individualistic cultures pay more attention to their own inner lives than do people in collectivist cultures…People in collectivist cultures tend to emphasize interpersonal relationships and gauge their well-being by looking at how those relationships are functioning (p. 239).

This statement is important with regards to the present study due to the reason that the participants' description of coping will need to be viewed through the norms of a collective culture and not through an individualistic culture. This will have to be taken into account when the data from the study is attached to Western theory.

Other differences have also been found between collective and individualistic cultures regarding the notion of self. Suh (1999) cautions that the concept of an integrated and separate self, which is the ideal of the traditional Western approaches to psychic development, may only apply to those people in cultures where autonomy and individualism are valued. This needs to be taken into consideration when discussing the experience of the women who participated in the study in terms of Western theory, and in particular, when discussing their experience using traditional psychodynamic theory. However, it is interesting to note that psychodynamic theory has been influenced by postmodern thinking and elements of this can be seen in the writing of more recent psychodynamic authors. According to Waddell (2002), in object relations theory:

> Internal conflicts now tend to be formulated in terms of the predominance of different aspects of the self, and of a person's struggle to become free of the deadening grip of narrow self-interest; to be more open to the truthfulness of intimate relationships; to have a mind of one's own and a respect for that of others (p. xix).

In this definition, healthy functioning according to object relations theory can be said to constitute both separateness, 'a mind of one's own' and authentic connectedness, 'open to the truthfulness of intimate relationships'. Although object relations theory sees the self as incorporating aspects of significant others, the emphasis on the formation of a separate self, which is core to object relations theory will need to be applied with sensitivity when considering African experience and perhaps the notion of self will need to be a little wider to accommodate the African cultural viewpoint.

3.5.1.4. Critical discussion of culturally-embedded psychology

This social constructionist approach, in which cultural process is elevated above psychological process, according to Varela and Harre (1996) contends that "human nature is cultural, it is lived socially, and therefore it is psychological" (p. 317) and that traditional psychodynamic views are incompatible as they hold the notion that "human nature is biological, it is lived psychologically, and therefore is social" (p. 317). In essence, social constructionism suggests that culture as opposed to biology determines the existence of a self. Gergen and Gergen (2003) highlight the importance of acknowledging the subjectivity of language, for example, calling a group of people a 'tribe' is "not a naming of the truth of how people cohabit together, but a constructed reality of a particular research community. In other words, social constructionism reminds researchers to be aware of their language and the realities that they punctuate with it.

In criticism of social constructionist theory, Jones (2002) states that the post-modern solution to questions of human nature, is to "relegate all psychological phenomena to statements at the purely verbal level" (p. 231). According to Jones (2002) social constructionist theory takes traditional depth psychology's notion of 'inner diffusioness' and instead refers to this as multivoicedness: "…and the coherence of the self becomes contingent upon cultural practices. Persons are seen as able to organize and structure

their experience only through the communicative protocols of their communities" (p. 346). Jones (2002) views this disregard for unconscious psychological process as "a case of throwing the baby out with the bathwater…that social constructionism might exclude dimensions of selfhood that were traditionally explored in psychoanalytical terms, and are still relevant" (p. 344). Jones (2002) views the postmodern claim that there is no 'self', other than the self we create through language in a similar light, stating that:

> The impasse of social constructionism is marked by the disappearance of the distinction between first-person experience and its representations in language. There remains only a talked about universe…Robinson asserts on Wittgenstein's behalf, "the connection between language and world is a practical one in which changes in language grow out of, and at the same time codify and facilitate changes in practice" (p. 282). My contention is that social constructionism, taken to the discursivist extreme, denies the practical connection at the level of the individual human being (p. 358).

Thus, the tension seems to lie in the debate whether there is a self that exists independently of language, an understanding of which theorists try to capture using language, or whether it exists only because theorists speak of a self. Perhaps the answer lies somewhere between all these perspectives. Gergen and Gergen (2003) state that "Whatever account we give of the world or self finds its origins within relationships" (p. 2). Hence, both traditional psychodynamic and postmodern social constructionist perspectives agree on the social nature of human beings and the significance of others in the creation of meaning. Perhaps there is room for a multi-layered approach to knowledge in which theories, which are acknowledged as theories and not truth, can be utilized for the concepts they offer in applicable contexts. For the purposes of this study, it will be assumed that all approaches hold value and that the self is a multidimensional concept, comprising biological and psychological imperatives toward development, and

that the development of this self is intertwined with relationships and influenced by culture and language.

Criticism for a culturally embedded psychology has also come from within the field of social constructionism. While Gergen and Gergen (2003) consider this new 'culturally embedded' psychology a step towards de-colonialising psychology, they identified problems with the theory, stating that "it remains a child of Western modernism" (p. 2) due to its hesitance to question universal metatheory, the fact that its methodologies are still derived from empiricist approaches and its resistance to reflexivity, which is due to the "empiricist metatheory that sustains the presumption of value-free inquiry" (p. 2). In light of this statement, it is important to clarify that while this study attempts to use a more qualitative research approach and engages in reflexivity, it does still imply the value of universal metatheory, albeit in an attempt to adapt the theory to incorporate a more African worldview. However, Gergen and Gergen (2003) also state that: "Most reflexive scholarship to date has adopted a critical posture, exploring the oppression, loss, and suffering that can result from particular constructions of the psychological world" (p. 4) and while they state that this is the most appropriate beginning to a reflexive process, they warn against unrelenting critique, as this typically divisive process could lead to 'culture wars'. Instead, Gergen and Gergen (2003) advocate a stance of 'appreciative reflection' when working with cultural considerations.

> Discursively constituted traditions are both essential and perilous. As we enter into co-ordination so does the world become meaningful to us. We acquire identities as particular people, along with interests, goals, ideals, and passion. It is within the process of relationship that a landscape of values emerges. Yet, at the same time that we generate and participate within a way of life, so do we close off options and separate ourselves from others. We fail to understand or appreciate that which is not within the tradition of meaning of which we are a part. Flexibility diminishes, and those outside the tradition often become devalued. They are "other", with different ways of making meaning, and possibly they are dangerous

to one's own traditions and values. Through communicative relations we can generate new orders of meaning from which new forms of action can emerge. Because meaning is a human construction, precariously situated within ongoing patterns of co-ordinated action, it is always open to transformation (Gergen & Gergen, 2003, p. 3).

Thus, while a rigid adherence to psychodynamic thinking would close off options and understandings, so would a rigid adherence to social constructionist understandings of the world. Traditional psychodynamic and psychoanalytic understandings are often accused of being Western and therefore not applicable to people from African cultures, however, this study posits that although it is important to be aware of the Western origin of the thinking that more traditional theories necessitate, for example, around ideas such as family structure and roles, and not to adhere rigidly to these understandings, it is also important not to throw the 'baby out with the bath water'. Concepts that have value from all perspectives should be considered. Instead of viewing psychodynamic understandings as Western and therefore irrelevant, perhaps these theories could be seen to be evolving with time and globalization, constituting over time a loose framework rather than a rigid pre-decided upon reality within which to understand unique societal, cultural and family dynamics on individual emotional development. After all, stretching social constructionist ideas, one could say that psychodynamic theories are just another way of punctuating or 'languaging' experience. The question that this study sets out to explore is whether this particular form of punctuating experience can be integrated with the participants' African understandings or ways of punctuating their stories.

3.5.1.5. Conclusion

Considering South Africa's history of oppression of certain cultures and today's HIV/AIDS epidemic, it is essential that we do not get caught up in a philosophical debate as to which approach to knowledge is better or more valid. Perhaps we need to acknowledge the consequences of colonialism, Westernization and globalization and find

approaches to treatment that straddle two worlds much like the participants in this study. This study with its use of more traditional theories attempts to bear in mind Gilligan, Brown and Rogers' (1990) statement that "in the move away from a narrative art to a science that rejects narrative art, psychology has lost an awareness of voice and vision" (p. 89), and attempts to use these theories in a manner that respects the narratives of the participants. Gergen and Gergen (2003) state that:

> Traditional research in both cross-cultural and cultural psychology tends to appropriate "the other" – making him or her intelligible in terms of the home culture. The other is described and analyzed in such a way that "we now understand". This goal of rendering intelligibility may be contrasted with one in which inquiry seeks to alter or expand the home intelligibility by virtue of incorporating or insinuating into it an anterior mode of understanding. The aim is not to place "the other" in a comfortable conceptual box, but to transform the very conceptual structure through which understanding occurs (p. 6).

Therefore, with reference to the above quote, this study aims to incorporate both African and Western perspectives, through respect to the stories of the participants and the cultural contexts from which they come, in addition to a continuous process of self-reflexivity, in order to integrate different "ways of knowing" into a body of knowledge that may offer the potential of new possibilities.

3.5.2. Traditional theory versus positive psychology

The very origins of positive psychology grew out of a criticism leveled at the psychological theories developed in the previous decades. According to Seligman, Rashid and Parks (2006) traditional methods of psychotherapy tend to view mental health as the mere absence of symptoms and Seligman and Csikszentmihalyi (2000) state:

"Working exclusively on personal weakness and on damaged brains, however, has rendered science poorly equipped to effectively prevent illness" (p. 8). According to Seligman and Csikszentmihalyi (2000):

> Psychology has, since World War II, become a science largely about healing. It concentrates on repairing damage within a disease model of human functioning…they [psychologists] came to see themselves as a part of a mere subfield of the health professions, and psychology became a victimology… Psychologists saw human beings as passive foci…drives, tissue needs, instincts and conflicts from childhood pushed each of us around…practitioners went about treating the mental illnesses of patients within a disease framework by repairing damage: damaged habits, damaged drives, damaged childhoods, and damaged brains…This almost exclusive attention to pathology neglects the fulfilled individual and the thriving community. The aim of positive psychology is to begin to catalyze a change in the focus of psychology from preoccupation only with repairing the worst things in life to also building positive qualities (p. 5-6).

As with any change, there will always be resistance and the resistance to the positive psychology movement seems to have been with regards to its name and its implication that psychology so far is lacking and therefore in need of redirection. Writing about the criticisms aimed at positive psychology, Gable and Haidt (2005) state:

> Many criticisms seem to arise from the assumption that if there is a positive psychology then the rest of psychology must be negative psychology, and if we need a positive psychology it is because this so-called negative psychology has taught us little. This interpretation is unfortunate and, more important, untrue…in fact, it is because psychology (which is mostly neutral, but with more negative topics than positive topics) has been so extraordinarily

successful that the imbalance, the lack of progress on positive topics,
has become so glaring (p. 107).

Despite the flattery, the traditional psychodynamic schools of psychological thought have attacked using the weapons they have and accused positive psychology of denial and splitting. According to Gable and Haidt (2005) a common criticism of positive psychology is that "…people who study positive psychology fail to recognize the very real negative sides of life, preferring a Pollyanna view of the world…the movement has cult-like qualities in which people get together to share their Pollyannaism" (p. 107). Positive psychology's response to this criticism is that those involved in positive psychological research are not rebels and that most of them are housed in traditional psychology departments (Gable & Haidt, 2005). According to Gable and Haidt (2005) the aim of positive psychology is "not to erase or supplant work on pathology, distress and dysfunction. Rather, the aim is to build up what we know about human resilience, strength and growth to integrate and complement the existing knowledge base" (p. 107).

This debate could be likened to the 'generation gap' in which the younger generation's decision to do things differently has offended the parents' sensibilities. Theoretical orientation is personal and tends to be based on the academic and cultural context in which the researcher grew up, therefore theory becomes as personal as values and beliefs about the way the world works. As difficult as it is for parents to have their children reject their views and develop their own beliefs about the world, it is difficult for disciplines to grow and incorporate new ways of thinking.

3.5.3. Motivation for combining theoretical approaches

For many theoretical purists, combining the theoretical orientations of analytical, psychodynamic and positive psychology approaches is riddled with epistemological issues, however, it is the author's opinion that employing an overarching epistemological

position, which allows for a multi-voiced approach, enables these three theories, when combined, to offer a new, dynamic view of the participants' experience.

Object relations theory and Jungian analytical psychology are in some respects fairly similar and hence, the combination of these theories is not inconceivable. The concept of dualities or opposites is common in many psychodynamic and object relations theorists' work. Freud's initial concepts of conscious and unconscious, id and superego are a clear example of this. While Adler described the inferiority-superiority complex (Ansbacher, in Schoeman, 1984) and Rank described a process of union versus separation (Schmitt in Schoeman, 1984), Horney (in Schoeman, 1984) spoke of the ideal versus the true self. A number of object relations theorists such as Klein (1935) and Fairbairn (1952) describe a primitive defence known as 'splitting', which entails the separation of objects and experience into 'good' and 'bad'. Fairbairn's structure of the personality contains a sense of duality with his concepts libidinal ego and anti-libidinal ego, with their respective internalised need-exciting and need-rejecting mothers. Winnicott (1965) also speaks of an initial symbiotic merger between mother and child that later moves toward separation and individuation. Winnicott (1965) also speaks about a false self versus true self.

It is the author's belief that Jungian theory can be used as a frame within which both sides of this pathology-versus-health debate between the traditional psychodynamic schools and positive psychology, can be seen as valuable and essential to the understanding of human experience. The focus of Jung's theory is on polarities, which provides space for both object relations theory and positive psychology to be explored. While object relations theory's focus on pathology could be seen to be exploring the illness side of the continuum, positive psychology's focus on health promoting factors could be seen to be exploring the health side of the same continuum.

While there may be a difference in the emphasis of one side of the illness-health continuum, both object-relations and positive psychology, by definition of their particular emphasis, imply the existence of the other side. Jung's theory and his emphasis on the move towards a sense of wholeness in life regards both the pain and joy in life as

essential to this journey. According to Compton (2005): "There must be a reason why people throughout history have been drawn to plays, paintings, poetry, and even music that express sadness, tragedy and defeat" (p. 12). Woolfolk's (2002) notion that the tragic elements that occur in life can enrich our experience of being human and the idea that much of life's meaning can be found in suffering (Frankl, 1985) point to the suggestion that "…it may be that in order to appreciate the positive in life we must also know something of the negative" (Compton, 2005, p. 12).

Also, an important contribution that positive psychology has made to the field of psychology is the finding that the predictors of positive emotions are unique. For a long time the assumption has been that if you eliminate negative emotions, positive emotions take their place, however, studies have found that this is not necessarily the case. The elimination of negative emotions often leads to a neutral state. In order to create positive emotion, further work is necessary (Compton, 2005). Fredrickson's (1998) 'broaden-and-build' model of positive emotion also emphasizes the role of positive emotion in 'undoing' the effects of negative emotion, assisting the "body and mind to regain a sense of balance, flexibility and equilibrium after the impact of negative emotions" (Compton, 2005, p. 27). Research has also shown that the intensity of negative and positive emotion are correlated, in other words, people who experience strong feelings of sadness also tend to experience intense feelings of happiness (Diener, Larsen, Levine & Emmons, in Compton, 2005). This suggests that people who are able to tolerate their negative emotions may be more open to life and their emotional experience of it, which thereby enables them to experience positive emotion more frequently and intensely. All of these findings seem to point to the fact that negative and positive emotion and experience are interrelated and without one, the other would not be experienced as such.

In positive psychology's quest to determine the predictors of or factors that underlie a subjective sense of well-being, a problematic factor was that of neuroticism, the well-known offspring of traditional schools of psychology. According to Compton (2005):

Let us recall that the third major component of subjective well-being is an inverse relationship with negative emotionality and neuroticism: the less neuroticism, the higher the subjective well-being. In many ways, this predictor represents that relationship. A reference to neuroticism, however, defines subjective well-being by what it is *not*. This way of defining an area is problematic…Researchers have found that the less fragmentation of the self or greater integration and coherence among aspects of the self-system, the higher a person's perceived subjective well-being…Therefore, personality integration may be a better description of what is meant by this predictor of subjective well-being (p. 53).

Personality integration forms the basis of the traditional approaches to psychology and implies more co-ordination and tolerance for differing aspects of the self, leading to "higher self-esteem, greater optimism, an internal locus of control, and better social relationships…and it may increase resiliency of the self" (Compton, 2005, p. 53).

It is however, important to note here, in light of the findings of the previous section, which discussed the fact that in collective cultures the experience of self tends to be one that is mediated by relationships with others, that the underlying tenet of object relations theory, which differentiated this theory from previous pleasure-seeking models of human psychology, is that humans are essentially object-seeking. In other words, we seek relationships and connection to others.

The majority of research done in the field of positive psychology, while exciting, tends to be quantitative, with a focus on certain variables at a time, which can result in a sense of static. Qualities, traits and aspects of personality that allow for coping and happiness are identified and there is a sense that people either have these qualities or they don't. While this is sometimes the case, the author feels that combining theories allows for a broader understanding of experience. While positive psychology can delineate the 'what and

when', psychodynamic theory seems to fill in the 'how and why'. Combining theories allows for a more in-depth focus on process.

As mentioned previously, research around HIV/AIDS seems to have followed the very human tendency of focusing on the crisis or negative first and as such, the literature has tended to focus on the negative sequelae of the illness. An illustration of this:

> The mental health situation changes quite dramatically where antiretroviral treatment is available. With longer life and hope for people living with HIV, the despondency and depression may be lifted (Rotherham-Borus, Lee, Gwadz & Draimin, 2001). Kalichman, Graham, Webster and Austin (2002) found that people who were not on antiretroviral treatment had a greater level of depression and greater pessimistic attitudes than those on treatment. However, it appears that to some extent treatment changes rather than obviates depression…the majority of physicians surveyed believed that HIV medications (antiretrovirals) are a leading cause of their patients' most common mental health problems… (Freeman, 2004, p. 144).

This statement is just one illustration of the research community's tendency to focus on the negative and while this focus is understandable and results in important and necessary work, research with this focus creates a picture of people living with HIV that is gloomy with a general expectation of decline in all areas of functioning. This misses a group of people whose experience does not match this picture and it is this group of people upon whom this research focuses. In order to more fully capture the experiences of this group of women, the author felt that a combination of theories offered an opportunity to view living with HIV from a different angle.

By and large, the people using these varied theories are essentially aiming to achieve the same goal, which is to assist people, within their contexts of relationships, to live their

lives more fully in order to achieve greater life satisfaction and greater levels of subjective well-being. While the more traditional schools have focused on removing the obstacles to this, i.e. working with the personality splits in order to achieve a greater coherence within the self, positive psychology has focused on finding the way to well-being i.e. identifying the predictors or markers to happiness. As a team, object relations theory and positive psychology could be compared to a path clearer and a navigator, both of whom are essential. Without a navigator, the path clearer might clear in circles, and without the path clearer, the navigator might know where to go but be blocked by obstacles. Perhaps together they might achieve their destination. Jung's theory could be seen as the glue that might integrate these approaches into a sense of theoretical coherence. The core of Jung's theory is to always incorporate both polarities: without exploration of all aspects of the self, the way might always be blocked and direction lost, which suggests that encompassing both polarities or theories may allow for a more holistic approach to understanding human experience and one that allows more options. So, maybe we should stop 'splitting', 'broaden' our awareness, 'build' our resources and get on with our 'Hero's Journey'.

3.6. CONCLUSION

This section outlined the theories to be used in this study, namely positive psychology, object relations theory and analytical psychology. It also offered a brief critical discussion around the use of Western theories in African contexts and mentioned some of the theoretical conflicts surrounding the theories to be used. A motivation regarding the combination of theories to be used in the study was also given.

CHAPTER FOUR

RESEARCH METHODOLOGY

There are two ways to live your life.

One is as though nothing is a miracle.

The other is as though everything is a miracle.

Albert Einstein

4.1. INTRODUCTION

In this study, a qualitative approach to research was used in order to gain rich, detailed information regarding the experiences of coping with HIV in the lives of ten African women. Semi-structured interviews were conducted and a thematic analysis was done in order to identify the important themes around the participants' experience of coping. These sub-themes and themes are discussed in chapter six and in chapter seven the themes are then interpreted and discussed according to positive psychological, object relations theory and analytical psychology. Respect is afforded to the participants' descriptions of their experience and chapter six attempts to stick as closely to the participants' experiences as possible with no theory being integrated at this point in order to gain a clear picture of the experience of coping with HIV as described by the participants. However, psychodynamic theories are integrated into the findings of the study which means that a psychodynamic understanding of the participants' experiences is generated, which is one of many understandings. So while this study is not a strictly postmodern study, it does utilize ideas that are congruent with postmodern thinking, namely, the use of a qualitative approach to the research; a multi-voiced approach i.e. acknowledging theories as providing different ways of viewing and explaining certain experiences; acknowledging the importance of context; and acknowledging the participants' lived experiences as valid data or information. The fact that the study uses a number of theories and integrates these theories with the participants' culturally embedded understandings of their experience to form a new understanding, implies an acknowledgement of the postmodern notions that context is vital for understanding and that no one theory is true or correct, but rather that they each represent one of many ways of understanding.

This chapter presents a rationale for the study and a description of the research process used in this study. It provides information concerning the research method used and the various stages of the research process. A brief theoretical discussion regarding qualitative research and the implications of the theoretical orientation of the study for the research method chosen, is followed by a brief motivation for the use of a qualitative

research approach, and in particular, a motivation is given for the use of a semi-structured interview format. The recruitment of participants and the data collection process is elaborated and an explanation of the data analysis process is provided. Lastly, reflexivity and ethical considerations are discussed.

4.2. THE AIMS AND OBJECTIVES OF THE STUDY

This research aims to describe the subjective psychological experience of women positively living with and dying of HIV/AIDS with the aim of identifying the significant cognitive, emotional and social themes involved in their subjective sense of coping, from a qualitative theoretical approach that aims to integrate positive psychology, object relations and analytical understandings. The objectives of the research are to:

- discover a more culturally appropriate understanding of these women's experience;
- integrate current theories in a new understanding that focuses more on the mental health promotion of women;
- provide further treatment options with which psychologists can work in order to provide an effective service to HIV-positive women patients.

4.3. RATIONALE FOR THE STUDY

The initial motivation for conducting a study into the experience of coping amongst HIV positive African women was the need for more research into HIV/AIDS, particularly in women, due to escalating prevalence rates (Freeman, 2004; Kalichman & Simbayi, 2004; Shisana & Simbayi, 2002). HIV positive women in particular have been identified as being at risk due to societal and cultural gender inequalities and due to their role as caretakers (Freeman, 2004). The decision to conduct a qualitative study was in order to explore the issues around coping with HIV/AIDS in depth. According to Lewis (in

Anderson & Doyal, 2004) understanding the lived experience of people with HIV is essential for the planning of appropriate health and social care and for the implementation of these services. Despite this, however, academic studies that explore the actual experiences of people living with HIV/AIDS are "few and far between" (Green & Sobo in Anderson & Doyal, 2004, p. 95).

It was felt by the researcher that an in-depth focus on coping as opposed to the mental health problems associated with HIV might yield useful information relevant to psychological intervention with HIV positive African women. According to Freeman and de Beer (1992) the mental health services provided to HIV infected individuals in South Africa have tended to originate from the medical model and have thus not been found to be empowering to users. Hence, this study aimed to explore understandings of HIV/AIDS related mental health in a way that is more empowering and culturally appropriate.

The rationale behind the choice of theories was multi-faceted. Firstly, the combination of positive psychology, object relations theory and analytical psychology is novel and no other studies have viewed the experiences of HIV positive women from this perspective. Secondly, it was felt by the author that all three theories have unique and relevant viewpoints that could contribute to a greater understanding of these women's experiences. Positive psychology offers a focus relating to the possible protective effects of positive psychological factors such as meaning, control, and optimism (Ironson et al., 2005). Ironson et al. (2005) found that higher levels of optimism predicted slower disease progression in HIV positive people. Lastly, the study hoped to integrate the more well-used traditional schools of psychological thought with a more 'positive' psychological paradigm, taking into account cultural influences, in order to create a more accessible and effective approach to understanding and dealing with the psychological aspects of HIV/AIDS for women in psychotherapy. For many theoretical purists, combining the theoretical orientations of analytical, psychodynamic and positive psychology approaches is riddled with epistemological issues, however, it is the author's opinion that employing an overarching epistemological position, which allows for a

multi-voiced approach, enables these three theories, when combined, to offer a new, dynamic view of the participants' experience.

4.4. THE THEORY BEHIND QUALITATIVE RESEARCH

As previously mentioned in chapter three (p 167), the tension that exists between modern and post-modern approaches, while providing fruitful creative space between them, is beginning to ease somewhat, with postmodern ideas being incorporated into modernistic psychodynamic approaches. The advent of object relations theory with its emphasis on the influence of relationships on the development of the self (Waddell, 2002) and the move away from the analyst as objective 'blank screen' toward a psychologist that is subjective and involved in the process of therapy or research illustrates this. More recent understandings of psychodynamic theory accommodate the notion of the therapist as involved in the process and no longer view countertransference as an 'interference', as Freud did, but rather view this information as a valuable part of the process of getting to know another (Waddell, 2002). Science as the 'only knowledge' seems to have made room for other approaches or ways of knowing, something acknowledged by Jung (1946): "Science is the best tool of the Western mind and with it more doors can be opened than with bare hands" (p. 78), however, "it…only clouds the insight when it lays claim to being the one and only way of comprehending" (p. 79).

Hence, while it can be seen that psychodynamic and analytic approaches accommodate the postmodern idea of the researcher as subjective, the fact that specific theories regarding development are delineated implies that there is still a large gap between postmodern notions of the self as entirely socially constructed and psychodynamic understandings of the development of self (see discussion on self in chapter two, p 29-34). This study aims to use psychodynamic theory in the interpretation of the data but attempts to maintain an awareness of the influences of society and culture on this development.

This section aims to give a brief discussion of the ideology behind qualitative research as well as to demonstrate how psychodynamic theory can be used with a qualitative research approach, taking into account the influence of societal, cultural and unique individual constructions of meaning.

Gilbert Ryle (1949) was one of the first to distinguish between 'thick' and 'thin' descriptions, using the example of a wink. While a thin description of a wink is the rapid contraction of an eyelid, a thick description takes into account the meaning of the behaviour and the context within which it occurs, thus a wink could be a parody, an expression of attraction, a twitch etc. Geertz (1993) borrowed these concepts of thick and thin description and discussed 'experience-near' concepts versus 'experience-far' concepts like philosophy, science and theoretical debate. Geertz (1993) focused on experience-near concepts in the direction of language and meaning and his theory became popularized in the postmodern ideas of construction, languaging and the narratives with which people present their lives (Anderson & Goolishan; Gergen & Kaye; White & Epston, in Krause, 1998).

The application of this experience-far and experience-near distinction to research methodology is evident in the divide between the two main research approaches. While quantitative approaches, which are concerned with how to convert qualitative data into reliable, objective numbers, free of context, can be considered experience-far descriptions of human behaviour, qualitative approaches, which are concerned with capturing and discovering meaning within a context in order to make it more accessible, can be considered experience-near descriptions of human behaviour (Neuman, 1997).

The ontological assumption underlying qualitative research methods is that people's subjective experiences are real and should be afforded the same respect as other forms of information (Terre Blanche & Kelly, 1999). According to Fordham (1953), writing on Jung's thoughts about the study of the human mind and experience:

There is no simple formula to which this [human] experience can be reduced; to focus on one point leads to a gain in clarity, but the network of relationships in which psychic activity consists is lost sight of. The search for precision in defining mental experience robs it of much that by nature belongs to it (p. 15).

Mental states, according to Neuman (1997) are regarded by quantitative researchers as merely conditions that lead to measurable behaviour. He states: "By contrast, qualitative researchers view qualitative data as intrinsically meaningful, not as deficient" (Neuman, 1997, p.328). The notion that people's subjective, inner, psychic experiences are real and should be regarded as valid data for study is supported by Jung as Fordham (1953) states:

This [Jung's] attitude towards the reality of the psyche contrasts strikingly with that to which Jung often refers as 'a nothing-but attitude'. Those who hold this point of view continually belittle psychic manifestations, especially experiences which cannot easily be connected with outside events, and refer to them disparagingly as 'nothing but imagination' or, 'merely subjective'; Jung, on the other hand, gives the inner or psychic process a value equal to the outer or environmental one (p. 17).

In qualitative methodology, the researcher comes from a position of 'not-knowing' and the epistemology underlying the method assumes that "we can understand others' experiences by interacting with them and listening to what they tell us" (Terre Blanche & Kelly, 1999, p.123). In this study, this 'not-knowing' position indicated by qualitative research methods was respected in two ways.

Firstly, the data itself was allowed to influence the focus of the literature study and while broad theoretical approaches were decided on before hand, the data was allowed to influence the focus of the theoretical discussion. Although object relations theory was chosen as one of the broad approaches to be used in the interpretation of the data,

precisely which theorists were used was left to the data to suggest. Theorists were chosen whose work focuses on the themes that emerged from the interviews. Allowing the data to inform theoretical choices was crucial for meeting the study's aim of expanding a Western-informed perspective in order to integrate a more African perspective.

Secondly, the 'not-knowing' approach was respected in terms of allowing the definition of coping to be described by the participants themselves. According to Compton (2005) one of the major challenges related to studying positive psychology topics like happiness, subjective well-being, resilience and coping "is the issue of who will define it" (p. 44). The ideological debate of who defines reality has led to much study around power discourses associated with knowledge. While modernism, at its worst, is associated with the use of science to marginalize people according to race, culture and gender, postmodernism attempted to shift this power and uncover the existence of knowledge in areas other than science, acknowledging many realities. Writing about this problem with reference to the definition of happiness, Compton (2005) states:

> At the time of Plato and Aristotle, many people thought that philosophers or intellectuals should define it for everyone. Later, leaders of Christianity believed that they should define happiness for everyone. In the twentieth century, a number of theories on positive mental health were proposed, but it was often hard to tell how the author's personal preferences and values influenced these theories…one solution to the problem was to use a very straightforward approach. Researchers began to allow the research participants themselves to define these terms. In this way the real judge of how happy someone was would be 'whoever lives inside a person's skin' (p. 44).

In the psychodynamic approach this would not be regarded as reliable information due to the existence of the unconscious and the fallibility of conscious explanations for one's own behaviour. In other words, a person may consciously believe that they are very

happy as a result of defense mechanisms designed to protect their conscious awareness from unacceptable unconscious impulses, which are felt to be threatening emotional experiences. "However, studies have shown that self-report and collateral reports often agree, suggesting that people who report a higher sense of well-being tend to behave in a way that suggests a higher satisfaction with life" (Compton, 2005, p. 44). From a psychodynamic perspective, in the cases where conscious reports may be skewed by excessive utilization of defense mechanisms, the use of clinical judgement on the part of the psychologist as interviewer and interpretation of the way in which the interviewee speaks about certain experiences may allow for the revealing of patterns of behaviour as yet unknown or unacknowledged by the interviewee herself.

Ryle's (1949) concept of thick description also took into account that some meanings may be so experience-near that they are expressed in unconscious patterns and are therefore not open to reflection. While some of the participants' unconscious patterns, as well as the researcher's unconscious patterns (self-reflexivity) may be reflected upon by the researcher during the analysis of the data, it is also likely that there will be some unconscious patterns that are not available for reflection at all.

Hollway (2001) writes about a qualitative data collection technique that uses a narrative interview, which is an interview that attempts to elicit interviewee's stories told from their personal, subjective experience. During the interview, participants are encouraged to follow their own structure and their stories are thus told with little interruption from the interviewer. According to Rohleder and Gibson (2006): "Within this approach intrapsychic conflict is understood to be activated in the participants when they talk of painful issues" (p. 30). Hence, the structure of the telling and the emotional responses of the participants "may reflect an unconscious logic" (Hollway, 2001, p. 15). According to Rohleder and Gibson (2006):

> This narrative, however, is subject to interpretation within which
> the interviewer follows the nuances of emotion in both what is
> said and what is left unsaid. The researcher's own emotional

responses may also help to inform their choice of where to ask probing questions to explore further areas that may be important. This method provides a framework for exploring defensive structures and unconscious expressions in the participants' narratives when talking about themselves (p. 30).

Hence, while it can be seen that the use of psychodynamic theory with qualitative approaches to research is not unreasonable, especially seeing as psychodynamic and psychoanalytic approaches have historically made use of the case study approach to research, which greatly respects subjective experience as a valid form of data, the most important consideration with regards to this study is whether the use of these theories compromises the meanings as relayed by the participants. In this regard it is important to defer to the aim of this study, which was to gain a deeper understanding of the experiences of these HIV-positive women from the theoretical standpoints of analytical, object relations and positive psychology. Hence, the meanings found by this study need to be read from this perspective and understood from within the context of the aims of the study.

So, perhaps, while we can think about theory as the hypothetical (Selvini-Palazzoli, Boscolo, Cecchin & Prata, 1980), perhaps we can view the interview material as involving grappling with the participants' realities (Krause, 1998) and the integration of the two as the creation of a new 'reality' among many possible realities. According to Hastrup (in Krause, 1998) there are many realities, each with its own continuity and its own practice, its own knowledge and its own partiality.

In qualitative research, understanding data within the context from which it comes is essential. According to Bleicher (in Terre Blanche & Kelly, 1999) in social sciences there exists the idea that "the meaning of human creations, words, actions and experiences can only be ascertained in relation to the contexts in which they occur. This includes both personal and societal contexts" (p. 125). This method is sometimes referred to as 'verstehen' (understanding) (Dilthey in Terre Blanche & Kelly, 1999) or

'empathic reliving'. Mischler (in Terre Blanche & Kelly, 1999) states that meaning is inherently and irremediably contextually grounded and that to grasp meaning one has only to learn how to gain access to the context. Jung's (1946) statement that psychologists' laboratory is the world and the tests are concerned with the actual, everyday happenings of human life, with the test subjects being patients, relatives, friends, and, ourselves, with the material being the hopes and fears, the pains and joys, the mistakes and achievements of real life, suggests that he had an appreciation of the fact that human experience is best understood within the context of the 'world' within which it occurs.

Another consideration in this discussion around qualitative research is that of language. The social constructionists' emphasis on the role of language in the creation of meaning has created an awareness as to the limitations of language (Gergen &Gergen, 2003). Much controversy exists around the question of whether language can adequately capture the essence of meaning. This includes whether language can capture the subtleties of cultural meanings. This argument is an old one within the social sciences and stems from the question: Can we really ever fully know the mind of another? While this concept is appreciated in the psychodynamic approach through the notion of the unconscious and the idea that there is experience for which we have no words, Tyler (in Krause, 1998) states that: "It is possible to make oneself understood in a language whose structure and grammar one does not know" (p. 70). So, while the experience of another can never be known in its totality, the parts that can be known and understood can contribute to interpersonal meaning.

Language is also important with regards to the presentation of findings in qualitative research. According to Terre Blanche and Kelly (1999) the interpretive or qualitative approach to research:

> …tries to harness and extend the power of ordinary language and
> expression, developed over thousands of years, to help us better
> understand the social world we live in…[interpretive research]

tries to describe in rich detail and presents its 'findings' in engaging and sometimes evocative language (p. 123-124).

The last consideration with regards to the use of a qualitative research approach is the notion of self-reflexivity, which entails sensitivity to the influence of the researcher on the findings of the study. Parker (1994) defines qualitative research as "the interpretive study of a specified issue or problem in which the researcher is central to the sense that is made" (p. 2). The concept of self-reflexivity will be discussed in more depth later in this chapter.

In conclusion, what appears to be called for ultimately is a compromise between cultural sensitivity, the aims of the study and an appreciation of the limitations of language. While the experience of the individual women is appreciated as unique; and an awareness of language and culture has been applied throughout interpretation; and sensitivity to the impact of the self of the researcher has been considered; the aim of the study is to find patterns of experience and ultimately interpret these patterns through theory.

According to Geertz (1993) any study is at the same time description and theory. He states that there are shared meanings out there in the world and that "societies, like lives, contain their own interpretations. One has only to learn how to gain access to them" (Geertz, 1993, p. 453). Culture can be considered to be a web of meaning rather than a series of patterns of behaviour (Geertz, 1993) and this study attempts to explore this web through tapping into the meanings of the participants within the context of their experience of HIV/AIDS and interpreting them according to existing theories.

4.5. MOTIVATION FOR USING A QUALITATIVE RESEARCH APPROACH

It is important to note that while the methodology of this study falls under the broad umbrella term of narrative research, no particular qualitative approach was chosen within which to situate the study. While guidelines for data collection and data analysis are

useful, a rigid adherence to one particular approach is not always necessary so long as the methods of data collection and analysis are adequately explained. According to Punch (1998): "Qualitative research concentrates on the study of social life in natural settings. Its richness and complexity mean there are different ways of looking at and analyzing social life, and therefore multiple practices in the analysis of social data" (p. 199). Thus, the methods used in this study are drawn from a narrative approach, but incorporate ideas regarding data collection and analysis from other authors, such as Hollway (2001); Kelly (1999); and Kvale (1996).

The aim of this study was to explore and describe the subjective experience of coping in HIV positive black women and qualitative research methods are particularly relevant for studying the lived, everyday realities of people in their contexts (Kvale, 1996). The wider and less-structured format of qualitative research approaches allows for the participants' narratives to lead the research process and this fit the exploratory nature of this study, as it provided an opportunity for the individual 'meanings' ascribed by interviewees to emerge. This was essential with regards to the meaning of coping, which was, for the most part, left up to the participants themselves to define.

Qualitative research interviews attempt to tap into the 'experiential world' of the participants and to gain an understanding of their 'meanings'. According to Kvale (1996) qualitative research interviews obtain subjective descriptions of the interviewee's world in terms of their interpretations of meaning. Knowledge evolves through the conversation between two people.

Thus, qualitative, in-depth, semi-structured, narrative interviews were conducted to explore the concept of coping from the perspectives of the 10 participants. The reason for this choice was that qualitative, semi-structured, narrative interviews would allow the interviewee more freedom to express her unique experience in its totality. Where a structured interview with set questions might have limited the study to previously decided-upon concepts in a certain manner of perceiving, to which meaning had already been prescribed, this form of interviewing allowed the participant to be involved in this

process. The majority of the researcher's questions emerged in the process as the interviewee's individual meanings become apparent. This style of data collection fit the exploratory nature and aims of the study.

The interviews consisted of a few open-ended questions to gain the participants' subjective narratives of their experience of coping with HIV. While most interviewer responses were designed to acknowledge and encourage the telling of participant narratives, certain themes were introduced during natural breaks in the interview by the interviewer, when necessary, to gain a fuller account of the experience – hence the term semi-structured interviews. The themes will be covered in more detail later in this chapter, however, it is important to note that attempts were made to gain an idea of each participant's history and current relationship network, due to the fact that in the case of HIV/AIDS in South Africa, as discussed above, context plays such an integral role in the experience, influencing further factors such as social stigma and in turn social support and access to resources, that any description attempted without taking context into account could lead to a more incomplete understanding. According to Kelly (1999) qualitative research is concerned with making sense of human experience from within the context of the participants themselves.

4.6. RECRUITING OF PARTICIPANTS

4.6.1. Coronation (Rahima Moosa) Hospital

The participants for this study were recruited from Coronation Hospital (officially renamed Rahima Moosa Hospital in February 2009), a women and children's hospital, in Johannesburg. This hospital is one of the Antiretroviral roll-out sites, thus there is access to HIV positive women.

At the time of data collection, the researcher worked in the Psychology Department of this hospital, which helped to facilitate the study. It ensured frequent access to the ARV

Clinic and sufficient time for the researcher to find possible participants. The relationships the researcher has with other staff members allowed for co-operation and referrals of possible participants from doctors, nurses, counsellors, other psychologists and dieticians working in the Clinic.

The nature and aims of the study were discussed with the Chief Executive Officer (CEO) of Coronation Hospital and verbal and written permission to conduct the study was granted. The nature and aims of the study were also discussed with the ARV Clinic Manager.

The Psychology Department runs open therapy groups every Wednesday morning for both adults and adolescents respectively in the ARV Clinic at the hospital. Nine of the ten participants in the study were found from the adult group, while the final participant was a nurse referred to the researcher by the Clinic Manager.

4.6.2. Selection criteria for participation in the study

Due to the exploratory nature of the study, there were very few inclusion and exclusion criteria. The first criterion was willingness. Only individuals who agreed to participate in the study were included. Verbal and written informed consent was gained. Further criteria were that the participants had to be black women in any stage (WHO HIV/AIDS Staging) of the illness, who are living positively with HIV. Women in any stage of HIV/AIDS were considered, as this might result in a broader understanding of the process of coping throughout the course of the illness. Living positively implies a sense of coping. Due to the fact that one of the assumptions of qualitative approaches to research is that the researcher starts from a place of 'not-knowing', the definition of coping, in as far as it influences inclusion criteria for the study, was left up to the participants themselves and the referring professionals.

One of the few exclusion criteria decided upon for the study was based on language. If the woman was not adequately able to speak either English or Afrikaans, she was not included in the study. The aim of this study was to gain an in-depth understanding of these women's experience and the medium through which this was to be achieved was language. An inability to express herself adequately in a language understood by the researcher would not have furthered the aims of the study. The use of a translator in order to accommodate women who could not speak English or Afrikaans was considered, however, it was decided that the use of a translator may hamper the rapport, the communication, and the understanding between between the researcher and the participant, which may have lead to less accurate representations of the participant's experience. The fact that this study represents only the experience of the English or Afrikaans speaking women who were interviewed needs to be borne in mind when reading the results and discussion.

Also, for ethical reasons, in order to avoid dual roles of therapist and researcher, patients being seen by the researcher in her capacity as a clinical psychologist at the hospital, were also excluded from participation in the study. Interviewing patients would interfere with the process of therapy and the fact that they are patients may interfere with the process of the interview in that, despite the fact an already established trusting relationship may have lead to more disclosure and richer information, this may have caused patients to feel exploited and would most likely have put pressure on the interviewer to take a therapeutic role during the interview.

The number of participants was determined by the number of interviews that it took to reach saturation – the point at which little new information was being gained from interviews and the research question was satisfactorily answered. Age was not considered to be a criterion for inclusion or exclusion and participants ranged in age from to 31 to 49.

Of 12 women referred to the researcher over the course of approximately one year, 11 were interviewed. The woman who was referred but not interviewed, cancelled her interview due to a death in her family, which subsequently led to her moving back to her family home in another province.

In the case of the woman who was referred and interviewed but whose interview was not used for the analysis, it was necessary for the researcher's discretion to be used in this regard. Upon discussion with the researcher's supervisor it was decided that the interview should not be used for the study as the interview revealed that the woman did not meet the inclusion criteria. As the interview progressed it became clear that the interviewee had some fairly serious unresolved conflict regarding her status and the loss of her partner. Personality pathology was present and she used the interview as a space to begin to access support for her distress and her concerns about her child. Her emotional reactions were contained and supportive therapy was arranged for her with another psychologist. A cognitive and emotional assessment was also arranged for her child in the psychology department at Rahima Moosa Hospital.

4.6.3. Definitions of coping

The researcher discussed with the staff of the ARV Clinic and the psychologists running the open therapy adult group the nature and aims of the study and requested that any woman whom they felt was 'coping' well was to be approached and asked if she would be willing to talk about her experience for the purposes of a research study on women with HIV who are 'coping'. If willing, the individual's name and contact number was then given to the researcher, who then contacted the participant with regards to participation in the study.

All the referral sources of possible participants (psychologists and nurses) were asked to give a brief opinion on why they thought the woman they had referred was 'coping' well.

When collated, these descriptions included:

- Women who communicated that they were coping
- Women who were able to participate in the psychotherapy group in a manner which showed them to be able to engage in emotionally congruent conversation around their experience of living with HIV
- Women who were able to be sensitive to the emotions of other group members, displaying empathy and insight
- Women who showed insight into their own struggles and emotional shifts over time in the group
- Women who were able to relate experiences of having overcome periods of emotional pain and hardship with regards to their diagnosis
- Women who displayed evidence of self-esteem
- Women who were able to disclose their status to someone in their lives and who related having supportive relationships

These descriptions were added to the descriptions of coping gained from the participants themselves during the interviews and were taken into account during the discussion of results.

4.7. THE DATA COLLECTION PROCESS

Qualitative researchers do not make clear-cut distinctions between the various phases of research, considering it more a process than a set of distinct procedures (Terre Blanche & Kelly, 1999). Thus, the phases are interrelated and data analysis began during data collection and influenced the data collection process, in that important themes brought up by the first few respondents were then added to the interview schedule. However, for the purposes of this chapter, each 'step' is described individually.

The data collection technique chosen for this study was qualitative, in-depth, semi-

structured interviews that were conducted with participants to explore their experience of living positively with HIV and dying of AIDS, due to the fact that this format allows for flexibility (Kerlinger, 1986). The interviews conducted conformed to the characteristics of a qualitative research interview as outlined by Briggs, 1986; Denzin, 1989; Douglas, 1985; Mishier, 1986; Spradley, 1979 (in Neuman, 1997):

- the beginning and end of the interview are not clear
- the questions and the order in which they are asked are tailored to the participant and the situation
- the interviewer shows interest in responses and encourages elaboration
- it is like a friendly conversational exchange, but with slightly more direction from the interviewer
- it is interspersed with jokes, asides, stories, diversions and anecdotes, which are recorded
- open-ended questions are used and probes are frequent
- the interviewer and participant jointly control the pace and direction of the interview
- the social context of the interview is noted and seen as important for interpreting the meaning of responses
- the interviewer adjusts to the participant's norms and language usage

It should be noted though, that although the interviews conformed to the above characteristics of a semi-structured interview, they were conducted with Hollway's (2001) qualitative data collection technique in mind. Hence, although they were semi-structured, the interviews also took on the characteristics of a narrative interview, which is an interview that attempts to elicit interviewee's stories told from their personal, subjective experience. During the interview, participants were encouraged to follow their own structure and their stories were thus told with minimal interruption from the interviewer. Only when the participant finished a story and a natural break occurred did the interviewer introduce a new theme. The interviewer also followed the nuances of

emotion during the participant's narrative and at times, used this to inform her choices as to where to explore further (Rohleder & Gibson, 2006).

Interviews were held at the hospital in the researcher's office for the purposes of privacy, on days that the participants were attending the hospital for other reasons, in order to cause the least amount of inconvenience for the interviewees. The nature and aims of the study as well as the method to be used were explained verbally to each interviewee by the researcher and a written copy of their rights with regard to their participation in the study was provided. The researcher's telephone number was also provided should any questions or discussion after the interview be required. Confidentiality was assured and then written consent was gained from each participant for the interview to be conducted and to be recorded on audiotape and for the information to be used for the purposes of this study.

In order to develop rapport the researcher engaged in some informal discussion with each interviewee before the interview proper was begun. During this discussion, contextually important biographical information was gained and the interviewees had an opportunity to ask any questions and discuss any concerns they had. This helped to put interviewees at ease and aided in gaining richer information.

The duration of each of the interviews depended on the interviewee, with the shortest interview taking 40 minutes and the longest lasting 1 hour and 40 minutes.

Open-ended questions were used as they allow the participant to lead the discussion and "expand on their answers, to express feelings, motives or behaviours quite spontaneously" (Rosenthal & Rosnow, 1991, p. 179). Certain questions were asked to all participants along various broad themes relevant to the topic, but some ad hoc questioning at the interviewer's discretion was also used to explore various answers or 'meanings' more fully.

An interview schedule consisting of a few relevant themes to be covered during the interview was decided upon beforehand (Terre Blanche & Kelly, 1999). The themes around which questions were asked were decided upon before the interviews based on the researcher's reading and clinical experience and were designed to elicit as much contextual information as possible in order to facilitate a wider understanding of the participants' experiences. It was felt that due to the researcher's five years of experience working with HIV positive women, both individually and in groups, that focus groups would not be necessary in order to establish an initial awareness of issues salient to this population. In line with a qualitative approach, the data analysis process began after the first interview and important themes that emerged in the first two interviews were added to the interview schedule. These included: the quality of their relationships before and after diagnosis, and any religious or traditional beliefs and the role of these after diagnosis.

The themes that were explored with all participants included:

- *Their sense of whether they were 'coping' or not with their HIV positive status and if they feel that they are coping, what this means for them.*
  This was included as a way to begin the interview and in order to explore the participants' opinions and experiences of coping. It was felt by the researcher that asking this question first would elicit spontaneous reactions particular to the participants' understandings of 'coping' that would not be coloured by other interview content.

- *Being tested: their thoughts and feelings upon diagnosis and how they felt that they coped at this time*
  The above theme was included next as a means of prompting each participant's telling of their narrative. It was felt by the researcher, drawing from clinical experience with HIV positive patients at the time of diagnosis, that the experience of 'coping' might differ from testing and diagnosis to later 'living with' HIV. It was felt by the researcher that asking each participant to share their story from the

beginning would elicit a more complete description of coping. The importance of eliciting participants' spontaneous narratives regarding a topic was read about in Wendy Hollway's (2001) article entitled "The psycho-social subject in 'evidence-based practice'".

- *What they feel gives them strength in their day to day lives*
  Reading in the area of positive psychology, the article 'Salutogenesis: A new paradigm' by D.J.W. Strűmpfer (1990) prompted thoughts around coping as 'strength'. It was felt by the researcher to be an open-ended question that allowed the participants to discuss anything they felt assisted them to cope with their HIV-positive status. In retrospect, this question allowed the participants to bring issues as diverse as social support, motherhood, religion and helping others.

- *Their thoughts and feelings around disclosure and stigma*
  An awareness of context is recommended when conducting qualitative research (Terre Blanche & Kelly, 1999). The South African literature around HIV/AIDS suggests that the experience of stigma and discrimination is intricately linked to the experience of living with HIV (Brown, Macintyre & Trujillo, 2003; Campbell, Foulis, Maimane & Sibiya, 2005; Fife & Wright, 2000; Herek, 1999; Macheke & Campbell, 1998; Shefer, Strebel, Wilson, Shabalala, Simbayi, Ratele, Potgieter & Andipatin, 2002). It was felt by the researcher that any exploration of the experience of living with HIV needed to include a space for discussion on any social stigma related to the illness that participants may have experienced.

- *Their thoughts and feelings about themselves as women and daughters and sisters and - possibly partners and mothers – before and after diagnosis*
  The Rohleder and Gibson (2006) article entitled ''We are not fresh': HIV-positive women talk of their experience living with their 'spoiled identity'' suggests that a large part of the experience of living with HIV entails shifts in identity, hence the researcher felt that an exploration of the identity of the participants before and after diagnosis may elicit useful information with regards to coping with HIV/AIDS. Other articles that supported the link between living with HIV and shifts in identity were Anderson and

Doyle's (2004) article entitled 'Women from Africa living with HIV in London: a descriptive study' and the Koopman et al. (2000) article entitled: 'Relationship of perceived stress to coping, attachment and social support among HIV-positive persons'. other research suggested changes in this due to HIV-positive status – explore these changes in order to ascertain any links to coping – especially since the African self is intricately linked to the other

- *The quality of their relationships before and after diagnosis*
  This theme was added after the first two interviews had been done, as it became apparent in these interviews that the phenomenon of changing relationship quality may be a common experience among women who are coping with their HIV positive status.

- *Their thoughts and feelings around illness and dying*
  This theme was decided upon in order to elicit narratives around coping with the reality of physical illness and death that HIV entails. It was felt by the researcher, based on her clinical experience with patients who were living with HIV and/or dying of AIDS that confronting this final reality is an integral aspect of coping with the illness. Patients who indefinitely avoided thinking about this aspect of the illness often seemed to be utilizing a manic defense (Winnicott, 1935) and during therapy, the researcher found that it was most often these patients who struggled to make sense of their situations, find meaning in the experience, or come to a place of acceptance.

- *Their hopes and fears for their lives*
  The importance of future plans and goals with regards to coping was read about in the Ryan and Deci (2000) article entitled: 'Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being' and in the Cantor and Sanderson (1999) chapter entitled 'Life task participation and well-being: The importance of taking part in daily life'. Hence, it was felt by the researcher that an exploration of the participants' goals and plans or lack thereof could yield significant information as to how participants made sense of their HIV positive status.

- *Some exploration of their early and current relationships*

  Psychoanalytic theory places emphasis on early development with regards to the development of later personality structure and styles of interpersonal functioning. With this in mind and the emphasis that is placed on context within qualitative research i.e. Kelly's (1999) notion that in order to grasp human experience an understanding of the social, linguistic and historical features that underlie the experience is required, the researcher felt that a sense of the early development of the participants might yield a more holistic and contextually grounded understanding of how these women cope with their HIV positive diagnoses and how they came to be able to cope. The idea of resilience and its origins were read about in the Werner (1995) article entitled: 'Resilience in development' and in the Arehart –Treichel (2005) article entitled: 'Resilience shown in youth protects against adult stress'.

- *Any religious and/or traditional beliefs and the role of these after diagnosis*

  This was the other theme that emerged from the first few interviews that appeared to warrant further exploration. Although it came up spontaneously in the first few interviews, the researcher felt that additional encouragement was needed in order to explore the participants' experiences in this regard. The researcher felt that the reason for this may have been due to the fact that the researcher originates from a different cultural background to that of the participants and that a statement of curiosity from the researcher seemed to invite more discussion around these areas.

In order to facilitate the emergence of the participants' stories as fully as possible, ad hoc questions around sensitive issues such as sexuality and depression were asked where appropriate. In order to avoid, as far as possible, respondents becoming uncomfortable and avoiding the question or refusing to answer, they were warned prior to the interview that questions of a sensitive nature would be asked. Although at no stage were any respondents obliged or forced to answer any question they felt uncomfortable to answer, Kelly (1999) found that warning respondents in advance that the interview will require

them to talk about intimate details of their lives, leads to a favourable degree of directness and openness on their part. This was also found in this study.

At the end of each interview, participants were asked for any further comments or thoughts that they feel may be important. Once the interviewee had left, the researcher then made brief notes containing clinical impressions or any other information that the recording may not have captured, in order to preserve the context of the interview as far as possible for analysis purposes later in the research process.

All in all, 11 interviews were conducted over the course of one year, however one interview was not used for analysis purposes as it was found during the interview that the participant concerned did not fit the inclusion criteria of the study. The number of participants was determined by the number of interviews that it took to identify clear themes and to ensure that the research question was answered. Although it is impossible to gain a complete truth, according to Kelly (1999) theoretical saturation occurs when:

> …new information no longer challenges or adds to the emerging
> interpretive account; when no relevant new information emerges;
> when category development is dense and rich; when relations
> among categories are well-established and validated; and when
> there is a sense that the theoretical account is nearing a complete
> and adequate form (p. 381).

Using saturation as a guide to know when enough participants have been gained is also known as 'sampling to redundancy' as any new information gained becomes increasingly redundant (Kelly, 1999). In this study, after 10 interviews the recruiting of participants stopped as there was sufficient material to know more or less what issues were paramount (Kelly, 1999).

After the interview, the researcher queried the participants' experience of the interview and any problems or difficulties were addressed. Some interviewees expressed that it

was emotionally difficult for them to discuss these issues at length, but all experienced the interview as an overall positive experience. A few of the interviewees stated that they hoped their participation would assist others in the future and expressed appreciation for the researcher's interest in the subject.

The interviews were taped and later transcribed by the researcher. The benefit of the researcher transcribing the interviews was that it allowed the information to become familiar quicker. Also, subtle information contained in the interview, for example, the significance of a long pause, a sigh or quiet laugh, was not lost, as might have occurred if an independent person transcribed the information.

4.8. DATA ANALYSIS AND ESTABLISHING STABILITY AND CREDIBILITY

An interpretive thematic analysis was the method of analysis that was used to identify the significant cognitive, emotional and social factors that played a role in the experiences of the women participating. The analysis of information began after the first interview and entailed a number of identifiable steps, based on those identified by Kvale (1996). It is important to note though that these steps tended to overlap and thus were not necessarily carried out in this specific order. According to Kvale (1996) the steps of data analysis include:

- reading and re-reading the transcripts to familiarize oneself with the information
- identifying meaning units (words, phrases or paragraphs)
- grouping meaning units into categories according to similarities and differences establishing stability by repeating the grouping process after a period of time has lapsed
- establishing credibility by involving the participants in various stages of data collection and analysis to clarify their 'meanings'
- developing descriptions within the categories
- discussing the results

The aim of the analysis was to describe the understandings these women have of their own subjective experiences of coping and to provide an interpretation of these understandings, from a third person perspective, using a combination of established psychological theories. These theories, once attached to the findings in order to present an integrated explanation of the phenomena, allow for possible new ways of understanding or new intelligibilities (Gergen, in Kelly, 1999). With regards to using object relations theory as one of the theoretical approaches, it is understood that it is impossible to know a person's internal structure, especially from a once-off interview. Rather, it is understood that inferences will be made with regards to likely internal structures based on theory and the participants' reports of their childhoods and relationships with significant others.

According to Kelly (1999) good research encompasses both the orientations of 1) developing an understanding of subjective experience and 2) providing an interpretation of 1). One of the methods that can be used to achieve this is that of using the perceptual and cognitive processes of immersion, unpacking and associating (Kelly, 1999). These processes were used during the thematic analysis, when meaning units were decided upon, integrated into overarching categories or themes, compared and described. During this process, the researcher attempted to be true to the voices being researched, while acknowledging that the research questions asked in the study were not necessarily the same questions the participants were attempting to address within their contexts (Kelly, 1999).

Kvale (1996) states that in qualitative research, analysis and interpretation begin at the start of the research process and are not confined to the formal analysis stage of the process. Thus analysis was already occurring when the researcher began reading relevant literature, during the interviews themselves and during the process of transcribing the interviews. However, the formal analysis was conducted according to the seven steps outlined by Kvale (1996), although, as stated earlier, the steps tended to overlap.

Step 1: Orientation to the Interview Protocols

The interviews were each transcribed by the researcher herself as soon as possible after the interview itself and then read through. Each time a new interview was transcribed the others would be re-read. This enabled the researcher to become familiar with the material. The time between readings allowed for new ideas and ways of thinking about the material to emerge. This stage corresponds with Kelly's (1999) process of immersion.

Step 2: Meaning units

The identification of meaning units began after the first interview. Each interview was analyzed in detail i.e. read and re-read and initial meaning units were identified. These meaning units took the form of words, phrases or paragraphs that seemed to the researcher to capture an important aspect of the participant's experience. This step corresponds with Kelly's process of unpacking. According to Krippendorf (1980) the units themselves and their meanings are not absolute as they emerge in the interaction between reality and the observer. These meaning units took the form of various emotions, perceptions, relationships and situations described by participants.

Step 3: Developing Experiential Categories

In this stage the meaning units were grouped into categories or themes according to similarities and differences. According to Aronson (1994): "All of the talk that fits under the specific pattern is identified and placed with the corresponding pattern" (p. 2). This stage corresponds with Kelly's (1999) process of associating. Defining each theme or category aided in deciding whether a meaning unit belonged in the category or not. The experiential categories that were common to most protocols were used and were eventually then combined or grouped together to form a set of broader categories or themes. Themes are identified by "bringing together components or fragments of ideas or experiences, which often are meaningless when viewed alone" (Leininger, 1985, p.

60). Although the uniqueness of each participant's experience is acknowledged, there were shared experiences that formed themes that ran through most protocols. According to Aronson (1994) themes that emerge from the interviewees' stories are then pieced together to form a comprehensive picture of their collective experience. This grouping of sub-themes into a few overarching themes through a meta-analysis of the sub-themes was regarded as the beginnings of interpretation of the data. Examples of these overarching themes are 'coping as a process of disconnection and reconnection' and 'coping as loss'. The "coherence of ideas rests with the analyst who has rigorously studied how different ideas or components fit together in a meaningful way when linked together" (Leininger, 1985, p. 60). This stage is also referred to in qualitative research as induction, where concepts are inductively developed from the data and then raised to higher levels of abstraction where the inter-relationships between the concepts are ascertained (Kelle, in Punch, 1998).

Step 4: Establishing Stability

The concept of reliability in quantitative research has an equivalent in qualitative research that is known as stability. According to Stiles (1993) stability refers to the trustworthiness of observations and data. In this study, stability was established by repeating the grouping process described in Step Three of the data analysis process after a period of time had lapsed. In this way, there was a chance for important information that may have been overlooked or interpreted in a certain way to be seen or viewed differently. After the initial process of identifying meaning units and grouping them into categories, these categories were then grouped into broader categories. In order to ensure stability of the analysis, collaboration with colleagues who have qualitative research experience allowed for further analysis. At this stage the data was shared and themes were discussed with two colleagues in order to re-check sub-themes and themes and establish stability. Eventually, five sub-themes were decided upon, with one of these being further divided into seven sub-themes. An over-arching theme that accommodated all the other themes was then identified in a meta-analysis. These themes are discussed in Chapter six.

Step 5: Establishing Credibility

Internal validity is the term used in quantitative research to measure the extent to which a study studies what it set out to. Credibility is the term used for this in qualitative research and refers to the correspondence between the way in which the participants perceive certain issues and the way in which they are portrayed in the study (Mertens & McLaughlin, in Muir, 2000). According to Stiles (1993) credibility is the trustworthiness of interpretations or conclusions made from the data. Credibility is most often established by involving the participants in various stages of data collection and analysis to clarify their 'meanings' (Kvale, 1996). According to Aronson (1994):

> When gathering sub-themes to obtain a comprehensive view of the information, it is easy to see a pattern emerging. When patterns emerge it is best to obtain feedback from the informants about them. This can be done as the interview is taking place or by asking the informants to give feedback from the transcribed conversations (p. 2).

In this study the former method was used. When unsure about an interviewee's meanings around a certain topic, the researcher asked further questions and used the interviewees' feedback to clarify their 'meanings' as well as establish the next questions in the interview.

Credibility also encompasses the issue of reflexivity, which can be maintained by the researcher by acknowledging the preconceptions he/she brings into the project with them and by looking at the data and its interpretation for competing conclusions (Malterud, 2001). Reflexivity will be discussed in more detail in the following section.

Step 6: Developing Descriptions within the Categories

Although this process began formally at the write-up stage of the research, it had already informally begun with the development of definitions for the various categories of experience in step 3. However, once the categories were decided upon, the researcher went back to the original protocols repeatedly to ensure what was being described was still representative of what the interviewees had said. Quotes from the transcripts were used during the description stage in order to ensure that these descriptions were as close as possible to the participants' meanings. As well as illustrating the process of analysis, including quotes also allows the reader to form their own ideas regarding analysis and assess the author's understanding.

Step 7: Discussion of Results

In this study, the results are written up in three stages. In Chapter five the participants are introduced and a summary of their life stories is provided using quotes in order to present their experience in their own words. This situates the sample i.e. contextualizes the data and findings of the study. In Chapter six, the sub-themes and themes are described without attaching theory to them. Although some theory was used to provide definitions of the themes, the researcher felt that writing up the results first, before attaching theory would aid in keeping them as true to the interviewees' experiences as possible. Chapter seven then provides an integrated discussion of the results including relevant theory. This also then retrospectively aids in building a valid argument for choosing the themes. According to Aronson (1994):

> This is done by reading the related literature. By referring back to the literature, the interviewer gains information that allows him or herself to make inferences from the interview or therapy session. Once the themes have been collected and the literature has been studied, the researcher is ready to formulate theme statements to develop a story line. When the literature is

interwoven with the findings, the story that the interviewer constructs is one that stands with merit. A developed story line helps the reader to comprehend the process, understanding, and motivation of the interviewer (p. 3).

The process of attaching relevant theory to the data is also known as deduction in qualitative research. This is a necessary process as according to Kelle (1995) in Punch (1998): "theory generation involves theory verification as well" (p. 201). Thus, according to Kelle (in Punch, 1998): "qualitative data analysis is a series of alternating inductive and deductive steps, whereby data-driven inductive hypothesis generation is followed by deductive hypothesis examination, for the purpose of verification" (p. 201).

With regards to the generalizability of the study, the aim was not to find one truth or way of looking at coping in women with HIV/AIDS that can be applied to all, but rather to explore other possibilities and integrated viewpoints in the hopes of expanding current viewpoints and theories to encompass other perspectives. Generalizability is not an aim of qualitative research, hence the results of this study attempt to offer insights and understanding, rather than any broad conclusions to be applied to a wider population.

4.9. REFLEXIVITY

4.9.1. Introduction

The researcher's cultural background, gender and beliefs are considered as playing an important role in the context of this particular study, as qualitative research encourages self-reflexivity. According to Stiles (1993):

> By revealing rather than avoiding the investigator's orientation and personal involvement in the research and by evaluating interpretations according to their impact on readers, investigators

and participants, qualitative research shifts the goal of quality

control from the objective truth of statements to understanding

by people (p. 593).

This statement highlights the issue of reflexivity, which can be maintained by the researcher by acknowledging the preconceptions she brings into the project with her and by looking at the data and its interpretation for competing conclusions (Malterud, 2001). Hence, the next section includes a brief discussion of the researcher's personal, work and theoretical background and the influence that these may have had on the current study. For the purposes of this discussion, the researcher will refer to herself in the first person, however, in all other sections the researcher is referred to in the third person.

4.9.2. Reflections on the researcher's background in relation to the current study

I was the first born child to married parents and spent the first few years of my life in Rhodesia, which soon after my birth won its independence and became Zimbabwe. My parents moved to South Africa in 1982 and have lived here ever since. Despite having fairly liberal and open-minded parents, in the context of Rhodesia's colonial past and the war for independence, I was raised with mixed notions about the significance of race. As a child and even an adolescent, I had important attachment figures in my life who were black and who were respected as a part of the family, and who represented safety for me. My first friend was my parents' housekeepers' daughter and colour did not matter. Upon moving to South Africa, I was very young and the majority of my school years were spent in sheltered ignorance about racial tensions. My years in high school saw the integration of black and white learners and in 1994, I was 16 and the changes occurring in the country seemed natural to me. The struggle for African independence from rigid, Apartheid rule seemed to resonate with my own angry adolescent strivings for independence.

The move to South Africa was extremely difficult for my parents, both financially and

emotionally, and the birth of my sister in the same year and my mother's subsequent post-natal depression saw the development of a precocious emotional awareness and self-sufficiency in me. Much like the women in this study, I helped a lot with my younger sister and felt it important to support and please my parents.

After my Honours year at University I travelled overseas and worked, returning after two years to begin a degree in Clinical Psychology at the University of Pretoria. The psychological orientation of the course was a combination of systems, social constructionist and psychodynamic approaches. During my internship and later work experience, I found that I lean more toward a psychodynamic approach to understanding in the work that I do. The fact that I have been in a 5 and a half year psychodynamic therapy/analysis has also impacted my understanding and emphasized in my mind the importance of early experience and relationships in the development of emotional and interpersonal functioning. However, my tendency has always been to integrate different theoretical understandings and take a slightly meta-perspective on them, suspecting that at their core, the majority of psychological theories overlap and merely use different language to describe their understandings.

The interest and motivation for this study was borne out of my experiences during my community service year, when I worked in a small rural hospital and in the surrounding township's clinic. This area of the country had not had access to psychological services before and I became somewhat of a novelty at the township clinic. The township felt like a bit of a melting pot where 'loxion culcha' was seeing the difficult integration of traditional African belief systems with new Western influences. I was struck by the immense need of the community and by the ease with which my so-called Western psychology could be used by so-called rural, African people. I found that with an openness to culture and the role it plays in experience, with African culture new to me and Western culture new to my patients, we muddled along and had some important and meaningful experiences together. However, it has also been important for me to acknowledge the anxiety and guilt associated with being white with its connotations of the oppressor and the previously advantaged in the face of the poverty and majority black

rule in South Africa.

It was also in my community service year that I came face-to-face with the reality of HIV/AIDS. My experience of doing pre- and post-test HIV counselling and sitting with people as they received their HIV-positive diagnosis revealed the agonising emotional pain associated with this disease. I watched some of those people with whom I had done the pre- and post-test HIV counselling, wither away and die over the course of a few weeks or months, and bereavement counselling was an everyday task. I became very involved in training lay counsellors and in the institution of Prevention of Mother-to-Child Transmission campaigns. I also started the first HIV Support Group in the area and it was the fear that people experienced walking into the room for the first session, afraid of who they may see and if they will see anyone they know, that introduced to me to the stigma around HIV.

However, it was the strength and resilience that I witnessed in my individual and group therapy patients that year that inspired this study. Often I would be awe-struck at the ability to re-engage with life after so much loss that I saw in the patients whom I accompanied on their journey from diagnosis to acceptance. The bravery and honesty of many of those patients will stay with me forever.

The next year I was offered a Head of Department job at the only government Mother and Child hospital. My years in this post entailed a vertical learning curve and a reinforcing in my mind of the importance of early relationships, which highlighted for me the importance of supporting HIV-positive women and mothers. While the clinical nature of the work has tended to reinforce a clinical and, at times, pathology focused way of thinking in me, the fact that the department is also an intern training facility has encouraged theoretical growth and constant reflection on the work I do. My own therapy has also promoted constant self-reflection. My recent move to work at a University has helped to refine my thinking around this project, as well as provided valuable impetus to complete it.

The journey of writing this PhD has also evolved my understandings of these women's experiences and to an extent the journey has reflected my own process. I think that a part of my initial motivation to integrate positive psychology with object relations theory was linked to my feeling that object relations was too pathology focused. However, I have realized that this feeling was in part due to my own struggles with dependency in therapy at that stage. I experienced my therapist's challenges to my self-sufficiency as difficult, feeling trapped between fear of dependency and subsequent loss and a sense that my overdeveloped self-sufficiency meant I was pathological or 'not good enough'. In essence, object relations theory and my therapist had to hold some of my own critical nature for a while.

I have experienced a variety of losses due to death in my life, from family to friends to intimate partners and the fact this study had two supervisors is also significant. The death of my initial supervisor, given the themes of death and loss in this study, seemed bitterly ironic at first and then sadly poignant. While his death was difficult for me to process, the experience allowed me to appreciate the importance of holding onto the value of his contributions as well as mourning all that was lost. My second supervisor has brought a different perspective and a questioning that has refined the study and kept it grounded.

According to Trevarthan (in Krause, 1998) the way we think and feel about families and our family attachments can appear to us to be inevitable and the only way they could be, which is not surprising considering that from infancy these attachments have been the mediation of experience for us. It is obvious that these attachments lie within a certain historical context, however, this and the fact that they are not the only natural way to be may not be that evident to us. According to Krause (1998) this is merely one of the risks related to studying aspects within a culture different to our own, however, the fact that so much of the work in the government health sector is with people from cultures different to my own, I feel I have developed a curiosity and openness to cultural difference that treats culture as integral to understanding the inner world of a patient. This and the fact that my own therapy process has caused me to reflect upon and question my own cultural

influences, has led me to believe that people are all unique and yet similar, and that although someone may be from a certain culture, this by no means fully determines their outlook or approach to life.

In fact, according to Krause (1998) an advantage to studying a phenomenon in a culture different to our own is that we may be more sensitive to certain behaviours, actions or meanings that may be overlooked by someone from within the culture. In early forms of anthropology, researchers were often encouraged to rather study cultures very dissimilar to their own to avoid confusion and the polluting of one culture with another (Krause, 1998), however, the postmodern emphasis on the inability to be completely objective has discredited this notion and suggested rather a heightened awareness of our own viewpoints and the influence this may have on the process and findings of research.

Krause (1998) argues from different points of view that a preoccupation about language as meaning and symbol does not help cross-culturally practicing therapists to understand clients with different cultural backgrounds. Krause (1998) states that:

> …responsible cross-cultural therapy must start with the therapist reflecting about herself. Such reflection ought to include not only an assessment of past and present intimate relationships but also an understanding of the wider socially constructed relationships and practices in which she participates (p. 6).

The choice of psychodynamic theory in this study echoes this sentiment with psychodynamic theory encouraging self-reflection. Although self-reflection has been around since the birth of psychoanalysis, with analysts engaging in self-analysis, the post modern notion of the impossibility of objectivity can be seen to have been integrated into the more modern psychodynamic approaches. According to Waddell (2002):

> These changing theoretical emphases are reflected in the

psychoanalytic method. Analysts and therapists have become
not so much detached experts as involved participants, reflecting
on their own conscious and unconscious responses which then
constitute less of an interference (as Freud would have believed)
than an indispensable part of the working method (p. xix).

So, while the fact that I am the oldest child in my family and that the role I took in my
family with their unique experiences and circumstances was one of being overly
responsible, self-sufficient and care-taking, I feel the fact that similar experiences were
found in the women in the study was not due to my imposing my story on theirs, but
rather a 'synchronous' (Jung, 1933) occurrence. Perhaps my story and the resonance I
felt with these kinds of women was what prompted my interest in their experience.

What did strike me as being culturally different between the participants and myself, was
the tendency of the participants to describe most of their feelings and experiences of
coping within relationship to others. While this is found in Western culture too, the
degree to which one's self and experience relates to others is less marked than in African
culture. So, where I would tend to describe coping as an internal experience, the data that
emerged from the study describes coping as an experience mediated through relationships
with others.

While this led to me thinking about how much of my experience, conscious and
unconscious, could be described as being mediated through others, I also found that while
the participants tended to describe their experience of coping in relation to others, some
individualistic notions did emerge, which may be as a result of increasing Westernization
and urbanization, or perhaps, have always been a function of the culture, merely less
emphasized. A re-reading of the transcripts was done in order to ascertain whether these
more 'individualistic' notions that emerged from the participants' stories were prompted
by my style of interviewing or were brought by the participants themselves. The re-
reading suggested, however, that this theme was brought by the participants themselves.

4.9.3. Conclusion

As my internal world has shifted, so have my understandings of the various theories and I think my own process of taking back some of my projections through therapy, has allowed me to think more clearly about the theories in relation to the participants' experiences. While I think I have tried as far as possible to think about the influence my experience has had on my understandings in this research throughout the various stages, I think it is impossible for my experiences not to colour my interpretations.

The fact that my experiences resonate at times with the experiences of many of the participants leads to the age old debate – which is whether having had a similar experience hinders or helps understanding of the other's experience? Did my perspective lead me to pick out certain themes over others? Did my perspective lead to me to understand certain of these women's experiences in certain ways over others? Did my theoretical choices influence the findings of the study?

The answer to these questions is yes, of course. However, in research, as in the process of doing therapy, I feel that as long as I am able to keep thinking and reflecting on what belongs to me, what belongs to the other and what belongs to both of us, I feel I am able to write a meaningful, integrated account of these women's and my understandings of their experiences, as reflected through psychodynamic, psychoanalytic and positive psychology approaches. So, while my integration may be just one of many understandings and is not intended for generalization to all HIV-positive, African women, I feel it is an understanding that captures the experience of these particular women and an understanding that speaks to the collective, unconscious stories in us all.

4.10. ETHICAL CONSIDERATIONS

Firstly, permission to recruit participants from the HIV specialist clinic was gained from the Chief Executive Officer of the hospital.

The second and most important ethical consideration in this study was that of ensuring the participants' rights to confidentiality. Disclosure of an HIV positive status is a sensitive issue, thus to allow participants peace of mind, names have been protected and identifying particulars were available to the researcher only and were excluded from the final document.

Thirdly the participants' right to informed consent was respected in that a detailed consent form accompanied by a verbal explanation was used to gain informed consent from potential participants. All participants were informed of how their confidentiality was to be ensured by the researcher, the aims of the study and the possible advantages and disadvantages to participating. Participants were encouraged to ask any questions they might have around the interview and research process, in order for any areas of doubt to be clarified. Participants were also informed as to how their interviews were to be used and how the final information is to be used.

Participants were given contact numbers for the researcher so that, in the event that any doubts arose around their participation, they could reconsider participation in the study at any time.

A specific ethical consideration with regard to conducting in-depth interviews on a topic that is sensitive and personal in nature, is that, according to Kelly (1999), even though informed consent was gained, sometimes:

> …the interview takes on a life of its own, and becomes almost like a psychotherapy session where the respondent discloses thoughts and feelings that she or he may not have previously admitted to having, even to her- or himself. In such

circumstances, the interviewer may feel that the exercise has been extremely successful, but the interviewee may walk away with a bad feeling, perhaps that they had been intruded upon, or had something taken away from them (p. 387).

To avoid these sorts of problems Kelly (1999) recommends that the interviewer ensures at all times, that the respondent is comfortable with the level of exploration and discussion. The researcher attempted to achieve this by checking on how the interviewee was feeling after a particularly emotionally intense subject had been discussed and by allowing the participant control of the interview through allowing them to refuse to answer certain questions or terminate the interview if necessary. These conditions were explained to all participants before the interview was conducted, however, at no time during any of the interviews did any of the participants refuse to answer a question or ask to discontinue the interview. The researcher's discretion was used around how much further to probe into any answers and during the interviews, the researcher found that participants regulated the 'level of intrusion' themselves, through the depth of answer that they were willing to give. Participants tended to repeat their previous answer if unwilling or unable to give any further insight into their experience of a certain event or time, and the researcher took this as a cue to move to a new area of discussion.

Another way that this study aimed to minimize negative experience for the interviewee, was that access to follow-up counseling with an independent therapist or counselor was offered, if at any time after the interview the interviewee felt that she may need it.

Lastly, as participants were assured that only the researcher and her supervisor would have access to the full transcriptions, and that identifying details would be removed from these, in order to avoid breaking confidentiality and also due to the length of the interview transcriptions, copies of the transcriptions are not provided. Using excerpts from the interviews is considered less exposing and was felt to effectively demonstrate these women's experiences and the themes that arose from these. Participants were

informed that the recordings would be kept locked in the researcher's home office and that they would be destroyed upon completion of the study.

4.11. CONCLUSION

This chapter provided a detailed explanation of the research method chosen for this study, the motivation for this and the theoretical approach within which this research method is embedded. The steps of analysis were also described at length. The following chapter presents the participants and their abbreviated stories.

CHAPTER FIVE

THE PARTICIPANTS

You ask my thoughts
through the long night?
I spent it listening
to the heavy rain
beating against the windows.

Izumi Shikibu – The Ink Dark Moon

5.1. INTRODUCTION

This chapter aims to provide a sense of context and also introduces the participants of this study to the reader. There were ten participants in this study and their stories are presented here in an abbreviated form. They will be referred to by a random letter for the purposes of confidentiality. At the end of this chapter, a few of the recurring themes that appear in these women's stories are highlighted.

5.2. BACKGROUND TO THE PARTICIPANTS

5.2.1. C

C is a 34 year old black woman who currently works as a cleaner/admin clerk at a school. She grew up in the Eastern Cape with both parents, 2 older brothers, an older sister, a younger sister and 2 younger brothers. Her eldest brother passed away in 2006 and she has a close relationship with her older sister.

C was approached by the researcher to participate in this study after she had been attending a few of the caregiver groups at the HIV clinic. Initially in the groups she was extremely shy and quiet, only giving input when directly asked. However, as the groups progressed, she developed confidence and expressed her emotions in a quiet but sincere manner.

During the interview C came across as a woman with a gentle strength. She was able to relay her experience clearly, openly sharing her feelings and inner thoughts. The researcher felt a strong sense of sadness during the interview, especially when C spoke of her husband and her children.

Growing up, C described being her father's favourite child, due to her having been sick a great deal as a child with bronchitis. She described having to spend 4 months in hospital

as an infant and despite the doctors telling her father to go home, he wouldn't. C described her parents' marriage as good, but stated that when she was a teenager, she recalls thinking that perhaps she should not get married because men 'talk too much' to women and she did not like the way that her father talked to her mother. She described how her mother was constantly tired and how her father would often complain if his needs were not met timeously e.g. food not being ready when he arrived home.

She completed Standard 8 and fell pregnant in Standard 9. This partner did not support her or their child. She later married another man and had 2 more children. She moved to Johannesburg to join her husband who had employment there. Her first born child lives with her parents in the Eastern Cape. She described her marriage as having been very good. She experienced her husband as extremely supportive and described their relationship as:

> It was…my husband was very, very nice…he was cook, to wash the washing, everything…he was very nice…even with the child…he was getting up in the night and sitting with the child like this (gestures rocking an infant) till we sleep again…yes…it was very good…open…if he wasn't liking something he was telling me…'C, I don't like this and this'…

C found out her HIV positive status in 1999 when her husband became ill. Her husband informed her that he was HIV positive but she didn't believe him until they went to the doctor and he had a blood test. He then said to her "I am positive…no, I am getting dying now". She was pregnant with their last born son at the time.

C's husband was hospitalized approximately one and a half years later and he was again tested for HIV and the doctor informed C that he was positive and recommended that she have a test. She then tested and was told her positive status. She described the experience as follows:

> I was sad that day…even it was day…it was like night to me…and my husband he was very sick…he can't talk…he can't make nothing…that's why I ask God why you take my husband before you take me…at that time…I was thinking, not praying, just crying, crying, crying…

She was with her husband when he died in hospital and she was ill at the time:

> …because my husband is dying…he is dying in front of me that day…he is sleeping in Helen Joseph…I am seeing him and sitting there the whole night…and…when I walk to the toilet and I am feeling dizzy there and I am lying down there, like the fits…and then I see the feet of the nurse and she is helping me to the bed…but now I am better…even then my face was black, black and I was thin…

During this time, C was supported emotionally by a woman who worked with her husband: "…that lady was very, very nice…a white lady…she would sit down to me and talk with me and pray with me…a very nice lady…and after [my husband] is dying she took me again to the doctor to take the blood again…". After her husband passed away, C disclosed her status to her older sister and her parents. She described her family as being extremely sad at that time, but very supportive.

C described being very afraid of the stigma around HIV and AIDS and feeling ashamed. She explained that she was scared to go to the doctor:

> I was scared all the people will be seeing me going to the clinic all the days and then they will be saying HIV…and at that time the people were saying HIV…it was a shame for me…even me I was asking why I get HIV…it was bad at that time…it was

hard…how did my husband get the HIV?

The following year C was hospitalized for HIV pneumonia at Helen Joseph. Her oldest sister visited her in hospital. Upon returning home, her youngest child was admitted to Johannesburg General Hospital for meningitis:

> …my son is getting fits and he is coming to lie down in Johannesburg Hospital for something in his head the doctor said…he can't to eat…he can't to walk…he is just lying down…so I am coming to Johannesburg Hospital to lie down with my son and then I am starting to pray…I was crying…sleeping in the chair the whole day and night…I am feeling sad…

Her son recovered and is currently doing very well. They both started antiretroviral treatment in 2007.

Around the time that her husband died, C described feeling very angry with God for letting her husband die before her as now she had to struggle on her own with the children, however, she now feels that God is her main support.

She believes that her children give her strength as she is afraid to die and leave them alone. C described feeling afraid to tell her children her status and the status of the youngest child:

> I am scared to tell them that I am positive…because they is too young…maybe they will be sad…on my own it is a hard thing…sometimes I don't want to cry in front of my children…I cry in the bed…because the 11 year old girl she knows everything now…when I am sick she is sad…

C is reluctant to become involved in a new relationship and stated that maybe if God can find a cure then she can have another relationship. She stated that she is afraid to start a new relationship: "…maybe he will give me stress and maybe he will not love my children and he will abuse them…he will not be like my husband…". She stated that she is coping and that "…it is hard and you know, I don't want a husband now anymore…I am fine like this…".

5.2.2. K

K is a 37 year old black woman who was retrenched in 2006. She was unemployed at the time of the interview. Since being retrenched she had been financially supported by her mother until her mother's death in 2007. K was looking for employment at the time of the interview. She is living in her aunt's house with her 15 year old son. She is a marathon runner and has run the Comrades twice and the Two Oceans once.

K was approached by the researcher after she was seen in one of the caregiver groups at the HIV clinic. During the group, she had made some insightful comments about fears that other group members had and the effect these fears were having on their relationships with their children. She was able to share her struggles in her relationship with her teenage son in a thoughtful way with the group.

K's mother had passed away 2 weeks before the interview, however, when given the option of postponing the interview, she decided to attend as planned. As the interview progressed, it became evident that the death of K's mother seemed to have re-evoked pain at previous separations from her mother, the previous loss of her boyfriend and the early abandonment by her father. She was, however, able to talk about these events and make the links to her current state of loss. K's English is not good and at times during the interview she struggled to express her thoughts and feelings. Despite this, she came across as a strong-willed and determined woman.

K grew up in Johannesburg and has an older sister. Due to the fact that she and her sister were only 1 year apart her mother couldn't cope and her sister was sent to live with an aunt. Her parents divorced when she was 5, at which time her mother moved into her own sister's house with K. K had no contact with her father until she sought him out a few years ago. She described a good relationship with her mother and experienced her mother as supportive, however, she recalled an incident where she was separated from her mother and the pain she experienced around this:

> …the thing is in 1985, I think, I was doing Standard 5…my mum sent me back to Northwest to…because I think there was a problem around Soweto schools, you know…my uncle…I used to ask this uncle…I have a problem about this, I need this, you know…he won't do anything for me, you know, like asking or telling something…no – I don't have money…I don't have this…you know, I have even now a hatred to my uncle for that…because I couldn't ask him…like…to buy me a jean or takkies or whatsoever…because even if I asked a school thing, he couldn't buy that for me. I have to go without clothes…from there…I was hiking and by then I was maybe 14 years old…so I come…back to Soweto…

K finished school in Soweto and fell pregnant at age 22. The father of her child did not support her or the child. She met another man at a cousin's funeral 9 years later and became involved in a serious relationship with him. He disclosed being HIV positive to her in the beginning of their relationship and she reported that she felt sad for him but that she didn't discriminate against him. They used condoms throughout their relationship. At that time, K was unaware of her own positive status.

She discovered her own HIV positive status when her child became very ill and was hospitalized at Coronation Hospital in 2003. He was 11 at the time and after discovering

his status, she decided that it was unlikely he would have contracted HIV from anywhere else and so decided to test. She described that time:

> Really – I don't know…I don't know…especially when I see the way my son was…because he was very sick...very weak. I just blamed myself…I just…ah because his father couldn't…not knowing what was the reason…after that month with HIV…

K first disclosed to her sister, then her boyfriend, her cousin and then her mother. She found it easier to disclose to her sister, boyfriend and cousin as they were all HIV positive and had already disclosed their status to her.

She described her relationship with her boyfriend as very good:

> …my boyfriend was very helpful, very helpful…if I …uh…need something it is going to be difficult for me to ask you, you know, I need this, you know, I need that…then he's going to do like maybe giving me money or whatsoever like without asking because… sometimes I remember he once asked me 'are you okay? What don't you ask me to help you?'…I'll complain anyway, I'll talk but I won't ask…at the end of the day I won't ask you, I need this or can you please help me with this, you know…so sometimes he couldn't…knowing everytime he helps me – ja, he was so very helpful. You know, I related the story to him why I had a problem not asking, you know…ja, he understood me…and he just told me – I am not like your uncle you know – its like…if you have a problem because…we end up sitting in the bedroom not telling anyone, you know, because there are a lot of people outside who are going to help you – but I'm sitting around the house or sitting the bedroom thinking whatsoever…so no-one knows that I have a problem – if I'm not

talking you know… talk, ja

This relationship lasted 6 years until he died in 2006. K talked about missing him a great deal:

> …because he was a friend, a brother, you know, everything to me, you know…eh…I don't want to think…ja, he was everything to me…for a long time…but I'm not…because my boyfriend passed away on June last year but not like…finished…you know…I can't get him over my head…even like at night I used to…like standing at the gate…till my son [came home] or its nine o'clock…I used to see him like coming…the car parked here…and then you know…that thing you know…I'm not like even now…I don't have a boyfriend because of it's difficult for me to move on and just stop that…just going on with my life…you know…I don't want anything to do with guys whatsoever…

K described her mother as having been a big support to her during this time and the loss of her mother a year later as leaving her feeling worried and sad. She explained that she does go to church if she is not running a race, but that after the death of her boyfriend and her mother she has been feeling angry with God and that it feels unfair.

She described feeling as if she is coping but also not coping: "…you have to do things for yourself anyway and you have to be strong…maybe in future, like…my mum passed away…I'm not coping, you know, but I know I have to stand up for myself…I have to be strong…especially for my son, ja…".

5.2.3. N

N is a 49 year old black woman who currently lives with her husband, children and stepchildren in Johannesburg. She grew up in Kwazulu Natal with her parents and 12 siblings. She was the 11th child of 13 children.

N was approached by the researcher after she had attended a couple of caregiver groups at the clinic. She was referred to the researcher by one of the therapists running the group. She was described by the therapist as coping, confident, open and invested in helping others.

During the interview, she spoke with a husky voice and gave detailed information spontaneously. She is a natural storyteller and her history of activism showed in the passion with which she related her opinions and experiences.

N described a deprived childhood, remembering how her father used to work for an aluminium factory and come home once a week with a small onion, a small mealie meal and a cabbage for 13 children and her mother, and then drink the rest of the money away. Her eldest brother was a bus driver who tried to help her mother with money, however, he died of TB. She recalled how she at age 9 would collect bottles for the refund and use this money to try and help her mother with food and a hot drink her mother used to drink. She described how her father would then come home and pour the sugar and mealie meal on the floor, asking her mother where she got it from, accusing her of cheating and beating her. After her father had hit her mother she would give her mother some of the hot drink. She described knowing that her father had another girlfriend.

N's mother died when N was 13 years old. Her father got married to his girlfriend and N described this stepmother as being involved in witchcraft and using this to separate her and her siblings from their father. She described having met her husband at this young age and staying with him:

> …like since my childhood I have been staying with him [her
> husband]…my mother passed away in 1978…so I have been
> struggling to raise myself…and then my father got married with
> my stepmother…and my stepmother was using witchcraft…she
> separated us from my father…so we have been struggling to
> raise each other…even for school…

N described having been an activist during her teenage years and described having
witnessed a great deal of violence and killing:

> …I was in SRC and I was a representative for my
> colleagues…and the one time I was nearly killed by IFP…you
> know those days how it was…the one time I go with my friend to
> a UDF meeting and the IFP came there and they grabbed one of
> my friends…she was stoned in front of me until she died…it was
> terrible…I ran away…I fled to Johannesburg…there were so
> many things happening in KZN at that time…but even later
> when I was living in town…there were riots and they burnt my
> house with all the furniture…

She explained that she went overseas to perform Sarafina soon after her Matric exams
with her performer boyfriend. She explained that her younger brother was murdered by
the IFP soon after she left.

N became a successful performer and still performs with her husband singing and
dancing. She explained that their lifestyle used to be unhealthy:

> …if I saw things I have been doing as an artist…it was not good
> for me…even for my husband…you see, he couldn't affect me if
> he was straight…even if I was cheating or he was cheating…but

we couldn't end up there…because of the devil things we were doing we end up being positive…uh…I could say that I was not cheating on him…I know he was cheating…I used to be a tomboy…I grew up with boys…I was afraid of people…he was my first boyfriend, since 1986…we have 3 children together…I didn't think of…of men before…before I met him…and then I met him…we did Sarafina together…we went overseas and that's where our relationship started…when we came back we stayed together but then he was cheating…that's when I didn't know about all those things until I got sick…he is ten years older than me…that's why I was so angry…I couldn't get all those things if it was not him…ah, I was angry…

N found out her HIV positive status in 2005 when she was hospitalized for 3 weeks with meningitis. She described being very angry with her fiancé at that time because he had known his status since 2003 but had been too scared to tell her until she was sick in hospital. She couldn't eat and lost a lot of weight as at first, she didn't want to take the antiretrovirals. N explained that she had told her fiancé to leave and that she didn't want to see him anymore, but that he had been extremely supportive during that time and changed his lifestyle in order to support her – coming straight home after work instead of drinking with friends. She described eventually accepting her status and recovering well on ARVs.

She and her fiancé married the following year and she explained how she thinks he is so supportive because he feels he put her in this position. N believes that she and her husband contracting HIV was a calling from God as it has caused both of them to become more religious and clean up their lives.

They have 3 children together. The 2 youngest children are HIV positive and N has decided that when the oldest of them is 12 she will tell them their status.

N has used money she earned to build her father and her siblings 2 houses in KZN. She described her current feelings towards her father:

> …whatever he was doing, I knew it was not him…he was a quiet guy whatever he was doing…now he is very old…he can't even walk properly…the person I am fighting with is my stepmother…she has 2 sons who are drinking and raping people in the yard…they even hit my father and then he doesn't tell anyone…if I get angry for him it is difficult…he is supposed to pray and ask God to forgive him before he dies…'you had kids and what did you do?' I tell him that he must pray and ask God to forgive him before he dies…I have done a lot for my family…

In the past 10 years she has lost 2 more siblings to HIV and described trying to warn her siblings to take care of themselves and protect themselves from HIV. She financially supports most of her family in KZN and the children of her deceased siblings.

Her work as an activist has continued and she currently works on a government project funded by the Department of Arts and Culture going into schools educating children about HIV and AIDS. She explained that she feels happy if she can help other people.

N's life has been hard and filled with loss and struggle, however her optimism and energy seemed to have enabled her to find resourceful ways to cope. Her constant striving for change for the better for her family and for others help her find meaning in her HIV positive status.

5.2.4. P

P is a 32 year old black woman who is currently the single mother of an 11 year old daughter. She works in her sister's hair salon.

P was approached by the researcher after she had been seen a few times over the course of about 6 months in the caregiver group at the HIV clinic. P is a pretty woman who dresses fashionably and who participates often in discussions in the groups. Initially she brought her dilemma with her ex-boyfriend and his abandonment of her and their child to the group, expressing both sadness and anger towards him. As time progressed, her confidence grew and soon she was able to support other women in the group and give her opinion on their struggles.

During the research interview she was open and engaged with the discussion. She was able to give a meaningful account of her process of coping and could identify the areas of her life in which she felt she was still struggling. At certain times during the interview, the researcher noticed the conversation becoming more therapeutic and took note of P's tendency to elicit a maternal role in the researcher. At other times, P came across as determined to be independent. This ambivalence may be related to P's relationship with her own mother and the mixed feelings P has in this regard.

P was the 3rd child of 4 children, with an older brother and sister and a younger sister. She was 2 years old when her parents divorced. She reported that the relationship between her parents was bad before she was born. Her father had been physically abusive toward her mother and had been in jail for robbery:

> …you know…my dad was also in jail for ten years and my mother had to wait for him…and she was suffering…food, kids, clothes…and then when my dad came back from jail he started to treat my mother badly…after me and my sister were born they

divorced…he was physically abusive…he used to beat her…

She reported seeing her father from time to time growing up, but being afraid of him because he was very strict. She reported that he did support them financially. Her father died after he was shot a few years ago.

P fell pregnant with her daughter at age 21. Her boyfriend at that time worked as an HIV/AIDS counselor. P first found out her child's status when the child was 4 years old, however, she reports being scared and unable to accept this and refusing to take her child to Coronation Hospital after this, rather taking her child to private doctors when she became ill and not disclosing the child's status. However, when the child was 6 she became very ill and the doctor advised P to take her child to Coronation Hospital. There she reported seeing a psychologist who helped her understand that having HIV does not mean you are going to die straight away and who helped her accept the child's and her own status.

At this stage she disclosed to her sister-in-law, who had previously disclosed her status to the family after her baby had died at 2 months due to HIV and after P's brother had passed away from HIV. She experienced her sister-in-law as supportive.

She was herself very ill at this time and was losing weight. She then started counseling and ARVs at Helen Joseph. She reports that she currently feels healthy.

During the previous few years when her child had been ill, P reported that the relationship between her and the child's father deteriorated:

> Ja…he was around when she first got sick…but not a lot…when she was about 3 he started to disappear…he stays in Pietermaritzburg…he used to come and visit…he is working with HIV and AIDS…he is a counsellor…but at that time he stopped phoning and he stopped visiting…but he pays the school

fees, ja…but all the things in a relationship they just stopped…I don't know why he did that…I thought maybe he has found someone there in Pietermaritzburg…but then I found out my child is HIV positive and what came to my mind was ok…that is why he is getting like this…maybe because he is working with it he went and tested and found out that he is HIV positive and then he decided to stay away and then not telling me…because my child was sick when she was a baby but I never took her to the clinics…because he was giving us money, so when I tell him she is sick he is depositing money and then I could take her to the doctor and then the doctors never told me to take her for a thorough check-up, maybe to take blood and then there was this doctor who told me to take my child to Coronation and they did a thorough checking and take blood and then they say she is positive

She experienced this abandonment as extremely painful and feels that only recently has he started to accept that he is not going to come back. She is reluctant to start a new relationship as she is afraid to disclose her status:

…and I want to meet somebody else…but my problem is that I have to tell them that I am positive, but I don't have guts to tell them…I think I am afraid that if I tell somebody I am positive he will run away…and then comes the next one and then that one runs away…(laughs)…and then after 5 years…they all know and they tell everybody else…they are going to spread the news…you know, you mustn't go to that girl…you see how fit she is…she's got this and this, you know…so…maybe I am not ready…

P has not disclosed her status to her mother as she is worried that her mother may not cope with the news. She reported that when her brother died of HIV, her mother was extremely distressed:

> …a problem for me especially was my mother…she cries a lot, so I didn't want to worry her because with my brother and my sister-in-law she cried…you know older people…they just think of death…thinking I am the one who is going to bury my child and my child is not going to bury me…I'm looking for my child to bury me, you see, stuff like that…she cries a lot…ja…you know…my brother's death…she didn't cope with it at all…she was even going to the doctor…getting sick all the time …stressed, I don't know…until she recovers…

P has, however, disclosed her status to her sister and she feels she gets a great deal of support from her. P feels that she is coping now and stated: "…it is like I have accepted that I am HIV positive…I am dealing with it…and as long as I am not getting sick or stressed by it…I am living a life just like any other normal people…"

At the end of the interview, the researcher was struck by P and her honest account of her initial fear and denial and by her determination to make sense of her emotional struggles.

5.2.5. S

S is a 39 year old black woman. She has 3 children, the youngest of whom is also HIV positive. She currently works as a nurse.

S was referred to the researcher by another hospital staff member who was assisting with recruitment of participants for the study. The referring staff member felt that S, in addition to being competent at her job, is an inspiration to many of the patients. It was

explained that S is able to use her own experience to empathize with and encourage many of the patients in the clinic. The referring staff member admired S's bravery in coming to terms with her HIV positive status and in her openness with colleagues and patients.

During the interview, the researcher experienced S as an intelligent, witty woman who has coped with loss and hardship with courage. Initially, the researcher suspected that because S works with HIV and AIDS she knew the 'right' things to say about living positively and coping with HIV, however, as the interview progressed, S's willingness to discuss the more difficult times of her journey with HIV and the frankness with which she expressed her feelings and her opinions, dispelled any thoughts of insincerity.

S grew up with her mother and father in Kwazulu Natal. She is the second born daughter and has younger brothers and sisters. She described a close relationship with her sisters:

> …you know, in our culture (laughs) there's no open communication with your father…we are closer to our mother…we don't discuss much things with our father…with our father we just exchange greetings and are you okay and then he gives money or whatever…and with my mother also…I don't know, we don't discuss everything…you discuss things with your aunts or your granny…unfortunately I don't have an aunt or a granny to discuss these things with them, which is why I prefer to talk with my sisters…

She described having had a difficult relationship with her mother: "…because my mother she does not say thank you (laughs)…she is that kind of a woman who expects…she always expects more…no matter what you do she wants more…"

She described working part-time jobs while finishing high school and being very independent from a young age: "…when I was in high school doing grade 11, I was working in the holidays, temporary jobs, with my older sister…we were starting to be

independent…so I started to be independent…"

S fell pregnant with her first child in her early twenties and did not marry the father of the child. She felt that he could not commit to her at that time. She went on to marry another man and have a further 2 children with him.

S first discovered her HIV positive status when her last child became ill and was in and out of hospital. She described finding out her child's status as a very difficult time for her:

> …it was very hard…I felt guilty…I was thinking maybe if I had tested during pregnancy maybe I could have saved my child…but the thing is I was ignorant about these programmes that are available, you know the PMTCT…I did not have much information about these programmes…(laughs) I was a nurse but I had no information about these HIV things…

After discovering her status she disclosed to her husband. She explained that he had accepted it. She reported that initially she did not disclose to anyone else, but that with time and as she learned more about HIV, she began to disclose her status:

> Ah…initially it was a secret (laughs)…I can say, initially…I don't know whether I can say I was in denial, but I didn't accept it initially…it was not easy to talk about it…I think I have accepted it, I can talk about it now…but its through, I think it is through the support, the support of my family…my sisters, my children, my fellow colleagues and my supervisor…they are very supportive…they are non-judgemental, I can say they have accepted that there is such a problem…even if I need to go for my appointments there is no problem…I know I can go…

She disclosed her child's status to her sister because her sister was helping to look after S's children and S felt that her sister should know how to protect herself. S slowly disclosed to her other sisters and has disclosed her own and her youngest child's status to her children. She believes it is important to be honest with her children and feels that she would like her children to be able to communicate more openly with her than she was able to communicate with her own parents. S feels that she cannot disclose her HIV positive status to her brothers or her parents:

> …I do have brothers but I didn't tell them…I don't want to hurt them…same like I didn't tell my parents, I don't want to hurt them (laughs)…at least my sisters…maybe it's woman…woman talk…they are understanding, they don't have a problem…in fact, I am scared to tell my brothers and my parents…you know…they are dependant on me…you know if you don't have information about this HIV you think that somebody is going to die maybe early and I don't want to traumatize them…

A few years later S's husband became ill:

> …the period he was…when he was sick…he got a bit better and then he was supposed to go back to work in May, but then he started getting these headaches…but it was diagnosed late…he was having meningitis…only when he started becoming confused I sent him to Helen Joseph and they did a lumber puncture and discovered that he is having streptococcal meningitis…but it was late…he was already having that confusion by that time…and he didn't survive…I felt bad by that time…because I failed…I failed to help him…I managed to help myself and my child…but I didn't hide anything, I told him…I

said he must go to Helen Joseph and get treatment…

She reported that after the death of her husband, she was struggling financially and was afraid she and her children would be evicted from their house. However, through support from a colleague, psychotherapy and legal advice she managed to make an arrangement with the bank to take over her husband's bond. She has also built a house for her parents in KZN:

> Ja, you know…I had a graduation party and I invited church people to come and my family and my dad, he was praising me…he was saying…everything in this home…I built a house for them…he was saying everything you see in this house it is because of her…you see this house, my daughter she built this house for me…it was the first time I was hearing that he recognizes the good things that I do…

S has recently again become involved in a romantic relationship with the father of her first child:

> …the father of my…my eldest daughter has come back…but a few months ago…not a long time…but I won't get married again…I told him my status the first day he came back…I told him I am HIV positive…I was thinking if he wants to run away he must go…but fortunately he didn't run away (laughs) …he just accepted it…he told me that he loved me even before…the thing that made us to break up was that he was young (laughs) you see, he was after me all along and I was running away because I was married to this other man…

S feels that the reason she copes is because she talks to friends and colleagues and doesn't hide her status:

You know if you hide things you get sick…you get sick…stress makes you sick…naturally I am a person who likes to talk…that is why I don't hide even my status from the counselors… I don't want to get sick. You know I feel energetic and alive…to keep something with me makes me not happy…that is why I am the talking type…anything, I talk about it and then I feel happy…I cannot cope with hidden things…

She also feels that her work with other HIV infected women and children helps her to make meaning of her situation. She stated: "…it empowered me (laughs) to help other people…"

5.2.6. T

T is a 32 year old black woman who is originally from Zimbabwe. Her husband came to South Africa in 1994 to find work and she joined him in 1996. They have 3 children - a 7 year old boy who is HIV positive and a set of 3 year old twins who are HIV negative due to T having joined the Prevention of Mother to Child Transmission (PMTCT) Programme at Coronation Hospital. T currently doesn't work and is financially supported by her husband.

T was approached to participate in this study by the researcher after she had attended approximately 3 caregiver groups at the HIV clinic. In the first group she was quiet and seemed to watch the other group members. She seemed a little wary of the therapists. However, over the course of a few months, in the following groups that she attended, she seemed to relax and her participation in the discussions revealed a sensitive, empathic listener. On more than one occasion she was able to spontaneously reflect and contain another group member's pain.

During the research interview, she was a little distracted as her twins were playing in the room next to us. She had brought them along as she had not been able to find childcare for them. Again, she had seemed a little wary of the researcher, however, this seemed to abate after she disclosed that she was from Zimbabwe. The researcher thought that perhaps she had expected a negative reaction to this news. As the interview progressed, it revealed a woman who was extremely concerned for her parents and family still living in Zimbabwe. She became tearful when discussing their situation there and the conversation left the interviewer feeling humbled by T's loyalty and commitment to her family.

T grew up in Zimbabwe with her mother and father and 5 siblings: "…we were 5 girls…we are 5 girls and 1 boy…but the boy he passed away and the one girl she pass away…so now we are 4 girls…".

She described her childhood as good and explained that as a young child she took responsibility for her younger siblings. She explained that this is a role she still fulfils today: "Ja…I was the one who was cooking for the family when I was young…because even my sister's kids…the one who is passing away…I am supporting her kids…to go to school…"

T first found out her HIV positive status when she was pregnant with her first child:

> Ja…for the first time I was very, very shocked…I was thinking that I am dying…I was crying…I was even scared to tell my husband…I found out when I was pregnant…I went to the Alexandra Clinic and they tested me and tell me that I am infected with the HIV virus…ja…until I gave birth I didn't tell my husband…when my child was 1 year old…he started to be sick, so he was admitted to hospital…by that time me too I was starting to be sick and I was admitted to Helen Joseph…so at the same time his father was going to him….to me…after that he

came here to hospital and they started to tell him that the child

was positive and they were saying that it cannot happen that the

baby is to be positive and the mother is not positive…so we

came to the hospital and we both test…they tested me and they

tested him…

T described the time she was keeping her status a secret as an extremely difficult time for her. She was afraid that she was going to die and worried about her children and her family in Zimbabwe who she is supporting financially: "Ja…sometimes I used to worry…who is going to look after them if I am dead…I worry…I worry also about my family in Zimbabwe…they are struggling (starts to cry)…it is too hard there…I need to be strong to help them…".

T described her relationship with her husband as good and explained her sadness and reluctance to tell him her status when she found out:

…he doesn't have a mother…he is looking after his father and

his small brothers…so I was feeling really shame for him…that

is why it was hard to tell him…I was scared to hurt him…that

maybe he would be so stressed that his CD4 would go down…ah

no…I was very scared...I did not know where to start…how can I

start to tell him…it was very hard…

After T and her child were both hospitalized and her husband found out the child's positive status from the doctor, T described that their relationship remained good and that he is very supportive towards her and the children: "…but now it is ok…he knows…and we are open to each other…it's fine…he is too supportive, he didn't do anything…if he find out that I am positive and he is positive…he didn't say anything…he just accepted it…and we talk now…".

Both T and her husband have not disclosed their status to their families. They rely on each other for support and on other HIV positive people they meet in the clinics:

> Ah no…they don't know…I didn't tell them [her parents]…I am scared…you see, my mother is someone who is having high BP…ja…because sometimes she is having a stroke and I am thinking that if I tell them that thing will come back again…there will be too much sadness… eish…no…I don't want to tell them…I am very scared…especially my mother…maybe she will end up dying…she is that person who gets too much shocked…even if I am sick I won't tell them…because I know her, even if I tell her 'mummy, I am sick' she will be too much worried…because even that time when she have that stroke…it was when my younger sister was very sick, she have an accident…she hears that my sister is sick and she have the stroke same time…

T described gaining hope from meeting people at the HIV clinics: "It helped me a lot…because at home there…most of the times I was feeling lonely and thinking that I am dying…but then at the time that I started to come here and join the other ladies I see that there are many other people outside with this sickness…"

She feels that she copes because she has been able to talk about her status and she described how she tries to talk to other women now to support and encourage them. She described how her relationship with her mother taught her talk about her worries:

> Ah…maybe because I laugh, even now…and I am too talkative…I like to get things out…my mother she is also talking too much…she is the one that taught me to talk and get things out…she was always talking and laughing…and people would

visit to talk with her…she was also helping other people…

5.2.7. R

R is a 38 year old black woman who works as a store manager. She has one 11 year old daughter. She is involved in a long-term relationship with a man who is HIV negative.

R was also approached by the interviewer to participate in this study after the first caregiver group R had attended. There had been a misunderstanding that morning and the nursing sister had not explained well enough to the caregivers the aim of the group and the fact that attendance was optional. R had been extremely angry at the beginning of the group and had expressed her irritation at being told to go to the group room and not knowing the reason. After the therapists had explained the aims of the group, R calmed down. This incident, however, led to an interesting discussion in the group, where members started to talk about their experiences at various hospitals and clinics where they felt they had been treated insensitively and with disrespect. During this discussion R took an active role in encouraging other group members to stand up for themselves and their rights. She spoke about the need to be "cheeky" from time to time to look after oneself and one's family. Although she did take up a good portion of the group space, she was able to listen to other group member's stories and respond with sensitivity.

During the research interview a few weeks later, R was able to engage with the process extremely well. Although she initially presented as fairly intimidating due to a defensive assertiveness that bordered on aggression, she relaxed quickly. She presented a coherent narrative of her 10 year journey with HIV and her comments reflected insight and empathy. She is a lively woman with a quick sense of irony and humour.

R grew up with both parents and 4 siblings. She is the middle child but described having to take responsibility for her two younger siblings from a young age due to the fact that

her two older siblings had moved out of the house. She described her relationship with her father as having been strained due to his drinking:

> Uh…you know…when we grew up...my father was drinking…and you know how when you are young and you want to go out to the clubs and have fun with your friends…and come back at about 10 or 11 o'clock…well, we knew that when we got back our father would just explode…and that's how it was…and when I grew up I felt like my father hated me…you understand…I mean, when we wanted things for school, he would buy it for us…but if you wanted clothes to look nice…he would never buy it…but at that time, you know, he was drinking…

R described her mother as having been submissive to her physically abusive father and explained that she often felt like she had to try to protect her mother from her father:

> Ja…my mum was around…but she was so quiet…she was like when a man is around you are not supposed to stand up, you understand…you are supposed to listen to him…which I think is wrong…'cos you know at that time that he was drinking he was beating her and my brothers…you know, I'm firm…if I don't like a thing I say you know what you are doing is wrong…the others couldn't do this with my father…you know, even my mom…but you know when I was angry and I thought ok, I can't take this anymore then I would tell him what he was doing was wrong……at the times that I did stand up to him…it was just because I thought that I could make him stop beating my mother or my brother…but it didn't…he just kept beating…

R explained how she is still the kind of person that will stand up for what he believes in and how she feels when people are treated badly at the hospital, she feels that she needs to stand up for everyone's rights and say something: "…even now…I am the one that is fighting…even in the hospital…the other people are just keeping quiet and I am the one saying hey, this is not right, you understand?"

R fell pregnant soon after she left school. She was in a relationship with the child's father and despite the birth of the child, they both lived with their respective families. R's daughter was a sickly baby and it was soon after her birth that R discovered her HIV positive status:

> Uh…about ten years…it was after my child was born…my child was very sick at about 4 to 5 months…and so we went to Baragwanath Hospital and they check us there and tell me that we are both HIV positive…and so I came home and told the child's father about what had happened and he said no, he did not want to get checked…and we started to fight about it…but you know, I thought for the sake of my child I need to do something about it…and so I went to a doctor…who sent me here because that doctor knows Dr C…so I came and saw C and ja…we have been coming here since 96……you know for me and my child to still be alive and be here today…you know that they told me first that my child would probably die by the time she was three years old, you know…blah, blah, blah…but then she went onto ARVs and now she is ten years old and me too…I am only on ARVs two years now and I'm still strong…so as long as I am strong my child will not die…

R described the time after she first found out her positive status and the positive status of her child as being extremely difficult. She disclosed to the child's father but he struggled to accept the diagnosis and did not offer any support to R: "…for the sake of my child I

just had to go…I even said to the father, come lets go, but he said, no man, I can't go…so I said, ok, that's fine and I did everything by myself…". Her relationship with this man did not last long after this.

R described feeling very alone at that time and afraid of the stigma surrounding HIV/AIDS. She felt that she could not disclose her status to her family:

> …you know…it was hard at that time…everyone was afraid of HIV and you would hear them talking about HIV and saying bad things about people with HIV…and it would hurt me…and eventually I just said…you know, not telling people about my HIV is eating me…you know, like when I am alone I can feel it come…it was like the feeling I have when I see someone really sick…and I feel scared…and it was hard to be alone…I don't know…how I coped…I don't know, really…because sometimes when I was alone I would just cry a lot…a lot, and the father, he was no help…and with my father being so strict…I was so afraid of what he would say or do…I couldn't tell him…he is a rigid type of person and wants things to go his way.

R kept her status and the status of her child a secret for 8 years but then after the death of her brother from HIV she became depressed and her father sent her for counseling. It was at this time that she decided that she would disclose her status to her family so that she could get help looking after her daughter:

> With me, at first I thought I was the only one in my family, but then I found out about my brother…he was also positive…but he passed away…it was because he didn't want to accept it…he was ashamed and just got sicker and wouldn't go to the doctor…and so he died…a part of me does feel guilty because…I tried to save him but I couldn't and he passed away…you understand? I was

thinking maybe if I had done things different, if I could have been hard enough…maybe he could have been here today…but he's gone and there's nothing I can do about it. I decided that I was not going to die of this HIV…I am not going to get sick…I will not get thin and I will not get grey… you know, it was 8 years doing everything on my own, with no-one knowing…but now, I decided that I needed my family to know, because what happens if I am not at home, if I am outside and my child needs to take her medication. So now, if I am not there, my parents they are there.

R also struggled to accept it when the time came for her to go onto ARVs. She described having fallen pregnant accidentally and deciding with her partner not to have the baby. The termination caused a great deal of physical strain for her body and her CD4 count dropped significantly:

And so I was afraid of the ARVs and I told myself I am not going to take these…and I was so afraid for my child taking the pills…but then eventually I got sick…you know, in all this time I have never gotten sick, I have never been admitted, but this time it was after I had a TOP and I lost a lot of blood and my body was weak…then I had to go onto the ARVs and it has been ok.

R has experienced the staff at the hospital as extremely supportive:

…it feels like I have friends here [the hospital]...there is support…here I can get counseling and it feels like they made it like HIV is no longer a thing where you can die…they teach you that you just have to take care of yourself…eat healthy…which is something that I try to do…but not always…(laughs)…ja, we

got a lot of support here…

This encouraged her to start to disclose her status to more people in order to gain more support for herself and in order for her to help other people:

> …and I also decided that I must be open with the people at work…because of all the doctor's appointments between me and my daughter…and it was like when I told people they didn't believe me because I look so healthy…it's like even now, when I am telling people that I have been HIV positive for ten years, no-one believes me. but now I am making a joke of it…I have friends who find out that they are HIV positive and I tell them, uh-uh, you know, I go to Helen Joseph to fetch my medication alone and I am not going to give anyone any, they must go themselves and take care of themselves…and I tell them that it not like they now have to separate themselves, they must enjoy every day of their lives…you know, it relieves you…you know, to joke…sometimes I even forget my tablets when I am at work and then it is ten o'clock and someone will go over the loudspeaker of the shop and say, 'R, R'…and then we have some funny words that they use so that I can know what they are talking about and then I remember…'R, R, it is time blah, blah, blah and then I am oh, I must take my tablets…it really does help to have people around you who know because they can help you to remember…

R began a relationship with another man 4 years ago and described this relationship as being a big support for her:

> …I have a boyfriend…I didn't for a long time…I was afraid I think to start a relationship but when I met my boyfriend 4 years

ago…we were friends first and I felt that I could trust him…he was pushing me for sex…and I wanted that too…but I was scared…one day I just thought that I must tell him, you know…take the chance…if he leaves me then that is how it must be…he is negative…but he accepted my status. He was sad for me but he still wanted to be with me…so we use condoms all the time and he gets tested…you know…he is a big support for me…he can listen when I need him…he helps with my child and they get on, you know…it is good…I was lonely for a long time…I didn't think I would ever be with someone again…sometimes I used to cry at night on my bed alone…it was very painful…

During the interview R then disclosed that she is a sangoma. A part of her journey with HIV has been being called to study to be a sangoma and she now uses this gift to help others:

...it was a few years ago…you know, the twasa…it was actually one day in the church…I was there and suddenly I just felt that I couldn't be there…I couldn't understand at the time but then when I started having dreams about my grandfather…you know, he was the one in my mother's family who had the same thing…I spoke to my mother about it and she was the one who said to me that I must go for the training…so, after a few months when the dreams kept coming and I started getting sick…I decided that I must go…I didn't want to be sick…so I went...

Interviewer: How was it for you?

Ah…it was ok…it was good…it is something from your family that is like a duty or something…like a gift…it is nice to help

other people…

Interviewer: Do you see a lot of other people…?

Not really, I just see some people when they ask…I don't make money from it…I think I am just good at listening to people's problems and helping them think of answers to the problems….

Interviewer: Do you think that this gift helps you to cope with your life?

Yes…I think so…it is like a feeling that my family…even if they are dead still supports me and looks after us…

R described how she thinks that learning to cope with her HIV positive status has strengthened her and taught her the importance of support and open communication. She explained that many of her relationships are better since then, including her relationship with her father:

Ah…when I am sitting down with him we talk…you know also, I think it also might have been me…you know, I was the brilliant one…he expected me to be something…and so when I got pregnant straight after school he was so disappointed in me…at least he confronted me with it…he said to me, but you are the brilliant one…I expected so much more…you were the one to look after everyone, but now look at the life that you have chosen…but you know, I have still made something of my life and my father can see that…so we can talk now…

At the end of the interview, the researcher was struck by R's courage and her determination to prove her father wrong and make a success of her life. She inspired a

sense of sadness as well as admiration in the researcher.

5.2.8. O

O is a 36 year old black woman. She is married and is financially supported by her husband. They have one ten year old daughter.

O was approached by the researcher after she first attended a caregiver group at the HIV Clinic. She is a likeable and engaging woman with a keen sense of humour. In her first group she was able to engage some of the more scared caregivers into participating and she displayed the ability to reflect other group member's feelings accurately.

During the interview, she frequently made jokes and smiled, however, she was able to engage with more serious conversation topics. The experiences she relayed revealed a woman with a capacity for tolerating deep sadness, worry and anger and the manner in which she recalled these events showed her ability to find meaning and even humour in some extremely hard circumstances.

O grew up with both parents, an older brother and 2 younger sisters. She recalled her parents' marriage as having been generally good: "…it was fine…my parents were fine…there was not a lot of fighting…" and described her relationship with her father as being particularly good: "…it was fine…he was a good man…ah, he loves me too much…I was the first girl…". She described her role as the oldest daughter as having to look after her younger sisters and take responsibility for them.

O first found out her status when her daughter was young:

> Um…2000…no, 2002…it was the nurse at the clinic…they don't
> force you to test but they say we should test but when I was
> pregnant I say no, until…then when my child was very sick the

one nurse at the clinic she talk to me, she say that we must test…for the sake of the child, so then we test….because my child was sick…she have herpes…on the skin

She described having felt extremely shocked and sad when she first found out, but explained that it was the other HIV positive women at the clinic that supported her and made her feel better about the news she had received. She described having gone home and told her husband the same night:

> Ah…I just go home and tell her…he didn't have a problem…he accepted it…he says maybe its better because then my child is going to get medication…you must go back…because when you find it out…you don't just get ARVs…you must follow the appointments and go there…ja, even he, he must go there…but he didn't go in the first time…

Despite the support of her husband and the other woman at the clinic, O explained that the first few months after she found out her HIV positive status, she was extremely scared and sad:

> Ja, it took some time…because when you are thinking about this dying thing…you know, it's bad…the first thing that comes to your mind is that you are going to die…I'm going to die…I'm going to get thin, thin, thin and the thin, thin hair…those pictures, when it comes on those things…what are the people going to say to me…laugh at me…but then I think everyone is going to die…I can get sick and die…I can get an accident and I die…so, I just have to accept it…(laughs)

O talked about a time she had become very ill and needed to be hospitalized:

Yes…I was very sick…I was having meningitis…first I was having TB and I was admitted…I stay there for 2 months…and then I after that I was getting alright…and then I got sick again…I was having meningitis and I was in Helen Joseph for 3 weeks…ooh, the things I was doing…the people was telling me…because I didn't see myself…they say I was taking out the drips and hitting other people (laughs)…I wake up and they had tied my hands…and my feet…and when I say please untie me…but then the other people they were saying…no, don't untie her please…but then I remember there was the one nurse who was saying, no she will be ok now, you can untie her…ja…I was thin, thin, thin…when there was air moving it was me (laughs)…

She recalled this time in detail and explained her fears:

I was thinking that I was going to die…I was saying all the time to the doctors…just let me die…and the doctors kept asking me, no, why do you want to die…the pain was bad…and I was thinking I am very sick, it is better for me just to die…I am tired of being sick…to die is better than to be alive…but then I got better (laughs)…and then I went home and I started to pick up…then I was thinking it is better to be alive…(laughs…then becomes serious)…I'm not scared of dying…I'm scared of way of dying…maybe I will get too much sick and then die…can't even do anything for yourself…takes a long time…but then the time I was very sick with the meningitis…I survived it…(little tearful)…ja, but then even my husband…he talks about that time I was sick and he laughs at me (laughs)…ah, remember that time you were in the hospital…

O described that she felt very angry with her husband at that time and that despite this, he continued to visit her in the hospital and encourage her. She spoke about how she appreciated this and how that hard time brought them closer together:

> [He] keeps on coming to me at the hospital every day…and telling me no, don't say that you want to die, you will be fine…but I was cheeky to him…I was insulting him (laughs)…but he keep on coming…even that I was insulting him (laughs)… ja…we can talk nicely…even the time when I was sick…he was coming to the hospital every day…and then when I was the first one to take the medication…and he was always reminding me…

She and her husband decided that due to their HIV status they would not have another child: "…my husband and me talked about it and we thought that because we are HIV, we are not going to have another child…we have the one…it was sad…I thought I was going to have another chance…you know, another baby…"

She went on to describe how she worries about her child and her child's future:

> Ja….when I look at her I am thinking how long will she live and she is saying when I grow up I want to be this and this…so I am thinking will she reach her goals…because she is sick...if I die who will look after her…also I worry for her to get sick…I was worrying when she was getting the herpes…I thought that maybe my child is going to die…but she is ok now…

O also described the loss of her oldest brother a few years ago and how this contributed to her fear of getting sick: "…because even my brother…he is not telling us what his sickness was…he used to be fat, fat, fat…and then by the time he was passing away he was thin, thin, thin…he said it was TB…I think maybe it was HIV but he is not telling

us…"

O reported that she is comfortable disclosing her status to other women at the clinic, but explained that she has chosen not to disclose to her family:

> Ah, my family…I am scared to tell them…you see my mother she is having high blood pressure, even if you tell her someone is sick, ooh she gets frightened, so I am not sure when I am telling her if she will understand it or what…she will shake and say…oh, my child…ja, if I tell her I am HIV positive, she will cry, ooh…what will she say…and I am having 2 sisters…I am scared…there is this younger sister and I wanted to tell her one day…but then I changed my mind…I am thinking, no, I am too scared…they love me too much…so maybe when I tell them about this…I am the big sister…so maybe when I tell them they will worry…

O reported that she attends church regularly but that sometimes when she is struglling to cope with status she feels God may be punishing her. When describing her relationship with God she said:

> I was thinking God is punishing me…what have I done? Why can't he take this thing out of me?...sometimes…(laughs) you know it is hard to be positive…I am thinking God is punishing me, so I just have to live with this…but then sometimes I am thinking maybe God is not punishing me…there are a lot of people with HIV…I am not the only one this happened…

O also described how traditional African beliefs are a part of her family's belief system and how she feels that the ancestors are there but that she does not believe that they have anything to do with HIV:

No…I think the people who have died are looking at us…but I'm not sure that that has anything to do with HIV…I once go there…to the nyanga…but I realize they not talking the truth…that I am bewitched…they were saying that there were people who were jealous of me and they want me to go mad…that I am bewitched…it was my other brother that took me there and the nyanga was telling me that there was another woman at home…by my family… who wanted me to go mad…(laughs)…so then I was looking for the lady at my family home and then there was this lady…and we ended up hating each other…me and this lady…but I don't believe this stuff…the nyanga just wanted my money…(laughs)

O also spoke about the stigma around HIV and the difficulty she experiences hearing other people talk about HIV and how people with HIV are all going to die:

Ah, when people are saying the words are eating her…and the people I work with they see someone who is getting thin, they are talking…and they are saying 'ah, if I was HIV I would hang myself' and then they are saying no, you know those people who are sleeping there and there and then in the end they are getting their results and they are three words…I am saying no, it is not like that…but they are saying yes, it is like that…you see him, at first he was fat and now he was getting thin…three words are eating him…in three years he will be gone…they are saying that…it is painful to me…but I am not saying anything to them…when they are laughing…I am laughing with them.

O feels that the reason she copes with her status is because she has been able to accept it and she highlighted the importance of support from other HIV positive people. She

explained that seeing others cope and survive gives her hope. She also explained how she feels that now that she has been ill and survived she can tell others at the clinic her story to encourage them and give them hope:

> Ah…I accepted it and that is what makes me strong…and when I see other people doing well with this thing and I am seeing that I am not alone with this…then you can take it out…because they are also HIV positive and they tell me not to worry…ja, you can take it out of your heart…then you feel relieved…and they will tell you their ideas too…I support others and they support me…ja, you know, the one time when I was at the clinic I saw this one lady that I work with…she was not my friend, I just know her from working…and she was sitting on the other side, you know where the people sit who are just getting normal sick…and I was saying to the lady next to me, Ah, you see that woman, I know her from work, she is going to tell the others at work that O is having a big file at Witkoppen…we have big files there…and my friend said, don't worry, maybe she is also sick…and I was hiding like this…but then the following month I see her again and I greeted her and I just kept quiet…and then the following month I see her again and she is also having a big file same like me (laughs)…and I said Hi, how are you? (laughs)…and then we spoke and I told her that I saw her before and she said, ja, I also saw you…(laughs)…and then the following month she was sitting next to me at the clinic…and then I told my friends you see, this was the girl I was telling you about from work…and they were saying…you see, the people on the other side…one day you find them this side…

5.2.9. E

E is a 31 year old black woman who is married with a 15 year old HIV positive son from a previous relationship. She is an entrepreneur who has a spaza shop with her husband.

E was approached by the researcher to participate in this study after she had been seen a few times in the caregiver group at the HIV clinic. During the first few groups, E had presented as a quiet, angry woman. Her participation in the groups had been defensive and at times attacking of other women who expressed feelings of vulnerability. She once told another group member: 'you can't cry…you have a child…you have to be strong for your child'. E's progress in the group was fast though, and soon she was able to bring her own fears and vulnerabilities to the group. It was revealed at this time that E had recently developed resistance to her ARVs and had been put on the 2nd regime of medication, which is, in essence, her last chance, as government healthcare only provides 2 regimes. She was able to bring this to the group in an emotionally congruent way and it was at this stage that she was invited to participate in the study.

During the interview, E presented as an intelligent and self-reliant woman. She was able to engage with the conversation in an open and insightful manner.

E grew up with both parents and was the oldest child of 5 children. She has 2 younger brothers and 2 younger sisters. She described a deprived childhood due to alcoholic parents:

> I can say…I've been strong all along since I grow…because we
> used to grow in a poor family…not to say it was poor but to the
> fact that drinking parents…my father was drinking, my mother
> was drinking…then my father was working…I think now he
> should have been a richer person, but he was an outgoing
> person…he didn't care if we were there or not…then when he
> would get the salary and comes with it in the house…he would

share it and then go with his money to drink…then he come back later and want the money he shared with my mum back…he want it back to buy drink and cigarettes…it was a difficult thing…when you have R2 you know you have to buy some grocery for my mother…so I grow like that and learning from the child that I had from a young age without a father…I say I don't have to sleep like this…I have to pull up my socks because there is nothing that can help me now…

She described a fairly distant relationship with her mother that seems to be characterized by ambivalence:

Ah…my mum…we grew like that but for now…I am not that close a person to her…the thing is that even when I grew up I was not such a close person to her…I don't know (laughs)…not to say I don't love her or what…I used to be a quiet person…even when they ask me 'are you hungry' I say 'I'm fine'…I was not a person that used to bother people…always wanting sweets and cold drink…no…my soul was just fine…I didn't want nothing from anybody or used to have that heart of looking for somebody and what they have…and saying 'oh, I want that'…I was just a normal person living his life…

Her relationship with her father was described as being difficult. She described angry feelings, but also insight into the reasons he behaved as he did:

…I hate a person who likes to fight…

Interviewer: So you were very angry with him growing up…?

Ja…(laughs)

Interviewer: Did he ever hit your mum or the children?

Ja…every Friday he was hitting everyone…after drinking I don't know what does that mind come from…okay, now I am drunk I have to fight…only when they are drinking did they start to talk…

Interviewer: What happened with you and the other children when they were fighting?

What can we do? We can only cry and say 'leave my mum, leave my mum'…because at that time we can do nothing to help my mum, because at that time there was no time we can help our mum and fight our father, but now we can say no and fight our father…(laughs)…we can beat him now (laughs)…they do have problems …they fight a lot when they were drinking…every week there is a fight…when it is Friday, it's a fight…the thing is that he was retrenched from the work, my father…so maybe that is when he thought he is not a person…he couldn't find another job…he had to stay at home and who now had to provide him with all those things he was doing…so he had to stay at home and didn't go out again…

E went on to explain that she had fallen pregnant at a young age and that she had not even realized that she was pregnant. The father of the baby had been a fair deal older than her and he had disappointed her greatly and not supported her:

Ja…but when I was falling pregnant I think I was stupid or what…I wasn't bleeding every month any more…but I didn't notice…I was blind…I was found out by my aunt…she took me

to the side and she ask me if I am pregnant…she ask me again and I say yes…then she want to me to tell the father to come here to the house…uh…I was stupid…I was in love with him but I was stupid…he had another woman somewhere else who was also pregnant…one day when I was at his house I pack out the drawer and I find an invitation card…to a wedding…ag, I was stupid…it was hard…because I fall pregnant when I was young and the father of my child didn't even support with a napkin or what or milk…at that stage I had to expect that child alone…together with my parents…he[her child] was all along sick…but I didn't know if it was HIV…since 1999 when I bring him here to Coronation…

E talked about her childhood with a great deal of sadness related to how alone and unsupported she had felt, but also with a determination to make things different and succeed on her own:

You know the thing that makes me strong again is that I am having everything on my own…I don't have to cry to somebody for anything…I have decided that even though I was suffering I was not a person to go to my aunt…my aunt is a person who is living with her own things…I didn't go there and ask her for things…I don't have school shoes…because she will be saying ja, when you are finished your school I will never be seeing you again…you will be on the street with your own money…ja, there was even the times…we used to get food at the school …free food for the children who don't have no nothing at home…but sometimes there was no food at school…no bread or what…and then I had to go back home for lunch…in high school lunch was one hour…and sometimes I would get there and there would be nothing…so I would go back to school but I don't say nothing to

my friends, hey I'm hungry, I don't have nothing…I just kept quiet…growing up like that…I didn't have any problem, I was just growing, it was just a thing on me…a simple thing…to stand up by myself…I would encourage other women to do that …not rely on a person…not even on the grant money…when they asked for the first time when I was bringing my son here…they ask me 'you, you don't want grant?' I say no…because when you put your money on a thing for something you didn't work for you will be stupid…you will not spend it the same as something you worked hard for…if you get it free you will be stupid…

E later met her current husband. She described having met him while she was still young and partying with her friends and described having been drinking with him. She described their relationship as good and explained how they have been through difficult times together:

Ja…it was too hard that time…because I had to take the child to the hospital each and every time…and on that money we were selling paraffin, it was too little for us…so we decided the time we sell 20 litres of paraffin we will buy some eggs…they were cheaper by that time…maybe R2 for half dozen…then we bought some eggs to extend the stock…it grows up…it grows up…we sell loose cigarettes sometimes…we didn't want to say…you know today I am starving for KFC (laughs) we didn't have that mind…we thought we have to open a tuck shop but we didn't have money…I was saying I must go to my aunt and borrow R500…it was like a joke at the first…because his family was around and they were working…but they didn't care about him…but I had my mother and she was the one who would provide us with soya mince…because they used to get those

groceries from the church…so we didn't have too much problem about eating…and we buy some smaller stocks…then it was God that helped us…and it grows and grows…now it is a full proper tuckshop…for now we are living at town…we were living in a informal settlement, whereby they moved us…but there was no electricity and no toilet…so we decided that we need to take a bond and we bought a house in K…west…

E speaks of her husband with gratitude: "The thing is that…I thank him…he's the quiet person…he accepted my status together with my son whereas he is not the one who made that thing…"

E described that when she first found out her status, her child was 6 years old and very ill. She described the struggle she has had with her husband because despite supporting her and her child, he still refuses to go for his results or get treatment himself:

> He [her child] was 6…and after they tested him, they suggested that we test…me and my husband…so we went to test in 2002…but he didn't want to go back for the results…so it was me alone that went for treatment… No…he doesn't know nothing…I think he knows…but he said that he doesn't want to kill himself…I don't know if it kills when you know your results…(laughs)…let me say…when they test him…they ask us if we should go to Helen Joseph to test or they can test us here at Coronation…they give us a referral letter to Helen Joseph and we can decide when to go…that's when we go back in 2002 because I was seeing that this man…his head is a stone…so when I go with him it won't help me…(laughs) ah…men are stubborn…even if you can say what they don't care about that…but I decided one day we go there and he agrees with

me…but then he doesn't want to go back for the results…

E described having gone to the hospital alone to get the results of her HIV test and the decision to tell her husband:

> Ah, you know what…it was so hard…I told myself that I have to tell him…I stay with him…by that time we were married…I couldn't keep quiet and keep things away from him, because when he found out what should I do…because at the first time when we meet…I always, always ask him…we've been through hell…we didn't work together and we were living in a shack. We were living by selling paraffin so… I always ask him 'when you have money you will leave me?' No (laughs) he says no. 'When I have something like this will you go with me. He says 'yes'. Then I told myself I have to tell him because he says he will go with me all the way…

E and her husband have decided not to have any more children due to the fact that they are both HIV positive. She also spoke about worrying what would happen to her children if she were to die and the fear of burdening her mother. E then spoke about the problems associated with this decision, especially since she and her husband had decided not to disclose their HIV status to their extended family:

> …I say 'no more'…I won't go back and to the side of the HIV…I say why should I have another child, because if I fall pregnant I can be fine at that time but then what will happen to those children later…and it will be another thing for my mum… that is why I don't want another baby…also with the HIV…but the black people you know, they want to know why I don't want another baby…I just say 'just'…I don't tell them….we have to condomise because we can infect each other…(laughs)…his

family even goes to the traditional healer to get muti for me to have a child (laughs)…but they do not know that there will be no baby…

E spoke about how her HIV status has had a positive effect on her life and how it has made her change her life:

> Since I have discovered that I am positive I have changed my life…because at the first time I have been into alcohol…I was going out and since I have found out that I am positive I leave all those things…and I didn't want another child since I know that…that's the thing that I'm looking forward to…to do with my life…I don't see any friends because I am busy all the time…I am self-employed…it is like a tuck shop…my job…I am only going out when I have a reason…not just…and the thing that makes me not to go out is that I have collected myself and going out is going to lead me to wrong things…(laughs)… because all my friends…we used to go out whole night, like that…and they are not collected now…even when I see them on the street…when I visit my mother I see my friends…but they have never changed, they don't grow…what is happening with these people…

E also explained how her role as the oldest child has meant that she financially supports her family. She also explained how her husband's role in his family is similar:

> Ja…even now…I'm still looking for them…the one who comes after me…he is working at KFC…he is the one who has never been lucky, he didn't get anything from me…but the other 3 they get a lot from me…I buy the 3rd one glasses, he didn't see well…then I took the younger sister to the college, she is now

working at the Krugersdorp municipality in human resources …then the last one is still attending school but I am looking for her…but both families…even from my husband's side is also the same problem…not to say that they are drinking but both the parents are not working, so we had to deposit the money every month…so that they can eat…

E explained how her role of caretaker has sometimes caused her feel angry:

I used to get angry…oh no, why should I be a first born because I had to carry so many things…when things are happening they call me…sometimes I think no, why should we go…(laughs) …just imagine an older person calling you to come and discuss their matters …(laughs)

When asked what E feels has helped her in her life, she explained that for the most part she has learned to rely on herself and on her husband. She explained that she is afraid to rely on others due to the fear of discrimination due to their HIV positive status:

…I can't say there is something that helped me…I helped myself…because I don't go to church…I used to go to church when I grow up, but since I met this man I don't go to church…I don't go anywhere, I don't party…the thing is I don't visit the friend…even the neighbour I go there when there is problems… but I don't go there and just sit for 2 hours…because the thing I learned from my neighbour is that when I was sitting there…she used to say 'ay, you know these people with HIV…AIDS is doing what, what, what'…I was thinking in my mind, this is a wrong person…I don't have to sit with this person…when she discovers that I am HIV positive, she will be going out again and

speaking to other people things about me…

E explained that she and her husband made the decision not to tell their families their status, but that recently she had made the decision to tell her mother, mainly due to the fact that she had been put onto the 2nd regime of medication and that she was concerned for the well-being of her son:

> Yes…she couldn't believe it…but I say that is how it is, I can't change it…she says why do you want to put me in a stress…I say it is like that, there is nothing I can change…she was thinking too much…not the fact that she was shouting…she say…oh, no why do you come with this bad thing to me now…do you want my stress to go up…I said to myself, keeping quiet, even when I keep quiet it won't help me. I had to tell him…because now I am on the second treatment…I didn't tell her all that, that they change the treatment and that they say this is the last treatment they can give me…I was thinking what would happen when I am lying on the bed…she need to know…

E spoke about her fear of becoming ill and dying and the difficulty she experiences thinking about being vulnerable due to her self-reliant attitude:

> Sometimes I am asking myself when it comes to this point, what am I going to do…why can I not die when I come to that position of AIDS…I don't want to suffer…because I have seen so many people suffering because of this sickness, and the thing that bothers me is that they know there are clinics and hospitals, but they just lie on the bed at home…they don't wake up and go to the clinic for help…you must seek for help at least…the problem is if you are lying in the bed who is going to take care of you… you rely on a person every time when you are sick… you don't

get up yourself to get water…you will be looking for someone to bring it for you… I don't want to rely on people all the time for things like bring me water, help me to the kitchen…that is the thing that is making me to stand up…I don't want someone to work for me…I want to work for myself…I learned so that I have to stand up and that I must work hard…it is not easy for me to just sit down…

E also explained her beliefs around God and ancestors:

I do believe in ancestors but not to say that I will be going all out on my life on that…because I had to live on that and I grew like that…

Interviewer: And with HIV…what do you think the ancestors have to do with that?

Ah…on that I don't think there is anything…it is just when I pray I used to call God and call them, I grew like that…I ask them where they are… to help me…the thing that I believe is that God is the creator and he created the ancestors…it is a process from God…

Interviewer: So they link you to God?

Yes…and they help you…sometimes there can be something that is coming to your mind, don't go there because you will get hurt or what…

At the end of the interview the researcher was left with a sense of admiration for E and the way she has coped with the struggle that her life has been.

5.2.10. M

M is a 34 year old black woman who is currently a single mother to an 11 year old daughter. She works as an admin clerk for a courier company.

M was also approached by the researcher after just one caregiver group at the HIV Clinic. She had a gentle way about her in the group and was able to reflect and contain other group member's feelings.

The interview with M was full of sadness due to the number of losses she has experienced in her life, but the researcher was struck by M's quiet optimism and the grace with which she has managed extremely difficult times in her life.

M grew up with both parents, but spent most of her time from birth to age 5 with her mother and her school going years with her father. Her parents lived separately most of the time due to the fact that her father worked in town and her mother lived in the rural areas, growing vegetables. She described a difficult childhood being the oldest child and having to take care of all her younger siblings and cousins. She also described having run away from home when she failed her O level exams:

> When I was little we stayed with my mother but when I was going to grade 1 I was the first one to go to stay with my dad in town. He loved me. I was in grade 1 he cooked for me in the morning, left food on top of the stove and he used to tell me 'when you come back from school – you eat' I was short ja, I would take my food, eat, put away the dishes until I was in grade 4 - I was alone with my dad. And my dad, he was cheeky – but he didn't like hitting.   But my mum, shooo…everything she picked up…(laughs). So with my dad I thought he understood me, but my mum, those times I even thought she doesn't like me when I asked my dad he said no, your mother likes you – you are the first born…everything is for over you. Everything at home, we were five - when she is calling

someone, she will call me – always I must come now - must come and help. Me…if we keep quiet all of us, then she is cross…I 'm like I failed at school – I was supposed to pass (laughs) Ja…Ja I was - I did my 'O' Level exams, then I got only three subjects and I ran away from home – didn't want to stay with my mum.   Do you know we used to be an extended family – in a four rooms house, we could be maybe ten or twelve with uncles from my mum's side, aunts from my father's side - I was the elder – my mum wasn't home - I am from school – I have to cook and look after my father and my aunts daughter – who was, my aunt was here, so she lived with my dad – they were – seven years – you know how seven year olds are, they need their mums. (laughs)   So I was the first one to wake up , boil water, I bath them, I clothe them, it was so crowded…I…when they are from school, they don't know how to put their socks - I had to find stockings for her . I think growing up made me strong. Ja   ja I think growing up there made me strong – because we could see come home from school you get in the yard, its dirty – you have to start with the yard, because my dad…I would start with the yard, go inside, clean, cook – now I'm in high school cook – I finish maybe past eight – I'm tired – I cant even study I will say – OK, I will catch up in the morning – I will wake up at three and study – I can't…with the aunts and uncles – they didn't care – I had to look after them – cook, do everything for them – these little one, my aunts daughter and my brother (laughs) they were a handful. I would go to school, because it was a thirty minutes walk – I go to school ten past seven - I had to go with them, leave them at their school, proceed to my school.   From school, I would cry they are dirty – you have to bath them …

M described a difficult relationship with her mother, which only improved after she had her baby and her mother came to stay with her a while to help her:

…I wanted to have my mother next to me but she was away and

when she was near me, it felt like she was tormenting me – maybe that's the way she loved me (laughs) because she will say 'give me the spoon' then you would take your time – maybe she picks anything, she will hit you – but I didn't like it, because my other sisters, she didn't mind a lot – maybe it's the way I looked at it. (laughs) ja, maybe…I didn't communicate well with my mum, but my other sisters you could find them sitting in the lounge talking - I couldn't do that, I couldn't (laughs)   They could talk, a long talk, laugh, everything, even when I came in joburg I used to, because I took my sister to school ….. all my sisters – I helped my father - they to go school so when I sent money, sending money for her then she would divert my money to my other sisters - I felt hurt. Why is she doing this… but when I get pregnant, she came, she help me with my daughter then I started working and by the time she passed away, we were starting to get along (laughing)

After M left home she met and married her husband. She described their relationship as good initially. She discovered her HIV positive status when she was pregnant with their first child:

It was in 1995 when I went for… I was pregnant – so it was my first visit at the hospital for test…it was horrible.   I was angry and I didn't know what to do…I didn't even tell my fiancée.   It was hard…the doctor said I had options – I can do abortion…but I was already six months. My mum was at home – there wasn't anyone to tell – it was me and my fiancé.   I was scared of an abortion…

She described a hard pregnancy keeping this secret and explained that only after the baby was born did she begin to tell people. She was initially afraid to tell her husband and her mother and the first person she chose to tell was her father:

I don't know, my mum was old fashioned (laughs) I was scared of that…maybe she was going to reject me, many things. Ja. I first told my dad, because I communicated well with my dad…ja…he used to be a truck driver and he travelled. I was staying in Parkhurst and he was staying in Victory Park so it was near, then one day he came – he was diabetic – so I cooked his favourite food then he came (laughs).   He saw what troubled me and he asked me what was wrong…I started to cry – I told him…he was sad...he was – do you know that I saw him with tears – because I am the first born at home and afterwards …ahh…my dad was always wise… he talked to me, because every time if he comes here from home or when I saw his truck in Victory Park, or would phone I am here, come, or I am coming …are you alright…(laughs)

M explained that she told her mother soon after she told her father, but that she suspected that her father had already told her mother:

I told my mum in…my daughter was born in 1995…I tell her when I went home Christmas 95 - I thought I better tell her first because she [her daughter] was already sick…she wasn't …….she was so small (laughs) they said she is short like you…….but when I go to the baby clinic I see kids like her age……you know ….So I told her…she was very supportive…maybe my dad told her – ja I think so…She gave me more support - because when she was born she came here…she took care of me for two months, then she went home. I was really scared to tell her by that time...I thought I should tell her while she was here… I thought I should tell…

When M finally told her husband he was angry but continued to support her and the baby:

> Telling him – hey, it was difficult, it was horrible – he was angry why didn't I tell him before.   When I found out, maybe, I don't know – but I thought he was going to leave me or was going to make me make an abortion.   I didn't want to go through that…[but he was] very supportive because when my daughter started to be ill…when he was, when she was six months, she was fine up to six months, she started diarroeha….., ja many things, and then when she was three years she was admitted to the clinic- they said she was broncho something….

Despite his continuing to support her and the baby, M's relationship with her husband changed after this and she described a time when she was depressed:

> …lots of sadness - that's why maybe I'm so scared to get deep into relationships -   my fiancé sometimes was not doing well… I'm very scared to be hurt – like the time when I was so depressed in '98 I could watch the TV but I couldn't see or hear what it was saying and my dad said 'you will die and leave your daughter and leave her … just get out of that relationship…but maybe I wasn't strong enough to get out of that relationship…ja, in '98 it was a problem…it was horrible…especially '98 – it was very hard…I think he was dating –(sigh) there was a distance between us you see, mmmm, you could see there was anything…if I was brave enough – I was going to walk out - then I wasn't - I was scared my child was sick – who's going to take care of her, who is going to give me money for the medication, you know to rely on someone – everything…

M's husband then became very ill and she described a very painful few months, nursing him:

> Ja, it was a very, very terrible time. Do you know when I took my fiancée home when he was ill, suddenly he collapsed and I took him to the hospital. I wasn't working by that time I was at home because I wasn't working - now I had to find job - he wasn't ready to go back to work because he had meningitis……so it was very difficult, I had to wake up in the morning, half past four, and do you know at night you won't sleep when some one is sick and making noise – it comes…he was always hot - then I had get up half past four to go to work - at work our people were always phoning how you feeling - there was a cousin who was staying with him when I was at work - come from work…get inside the house…he's sleeping, did he wake up…eat little - you know, those things…it was only four months - it wasn't long - but it's because I got false hope when he was from hospital he wasn't working also, so he did the physio…he went to hospital in March and April he came out of hospital, he did physio, he started to walk nicely, he started to pick up, eat, you know - go out - go somewhere maybe to work, then one day when I come from work I found him sleeping 'did you go today' 'No I couldn't – I m not strong' 'I don't have energy.' So I said maybe its one of these days. The following day struggling to wake up then I said 'again' …what happened was so bad - it only took him a week…couldn't walk again so I took him to…I asked the uncle to take him home - we were maybe six months in arrears on rent so the landlord took everything, everything - so I went home, I took leave… apart from only two days, he passed away so when I came back I had nothing, I only had my daughter - my work…there were temps - you wait three weeks relieving someone, you wait three weeks then there is nothing - you work when you have something - and now you have to parent, pay school fees, buy food, that time it

was…

M's husband passed away and then 3 months later, her father passed away. She described an extremely lonely, painful time of her life:

> Ja. My…D, my fiancée, passed away in June…my dad passed away June, July… August – Ja…that was a hard year of my life…it was like drifting…it wasn't me walking.   I remember I collapsed on the train going to work one day - it was hard, very hard.

Two years later, M's mother and brother passed away and she described how her siblings pulled together:

> No…they all passed away, my mum passed away in 1997…So we are all kids left.   Its alright because we are very close…I have lost a lot - at home I have lost my mum – my brother was hit by a car… it was a hit and run and then he passed away they said…and my dad…

M spoke about how she recovered from the two years of loss in her life and how she saw her sister, who is also HIV positive, struggle to cope:

> …I think so, you know, I coped when it was very hard, then now I think I am getting there…because this other sister of mine who is HIV-positive too, she wasn't coping, when her fiancé passed away, 2004 she wasn't - she was so…after two months she was so…she didn't come out of the house she was all locked up in her bedroom, then she became very sick, I think that was the stress - she had nothing to look forward to – I had my

daughter…

M talked about how her daughter has given her reason to fight the illness and how her daughter's struggle with HIV has given her inspiration and hope:

> It was especially… I would look at my daughter and say now it was 2003, ne, she was how old…nine…she was nine, nuh uh she was eight   I would tell myself but she is strong for…four or five years, she is eight now – why can't I just have the strength - I think that pulled me through, my daughter – think positively – think positively – ja.

M also spoke about the role of caretaker that she still plays for her siblings:

> So I have to, everyday from Metrocard, phone all of them, my brother , my other sister…hey this one is tough - the one who stay here – this one, the other one – the one who is taking ARV's, she wants you to phone every day, maybe she depends on my support. You didn't phone to ask how I (laughs)…so everyday I have to…. I am used to it – I am like a parent to them. I have told myself that…do you know you have to especially when you don't have parents because when my dad passed away my brother was in form 3 and he was in boarding school…there wasn't money – I had to pay – he finished boarding school, he stayed at home a year, he went to work at…he didn't like it there – so I had to do a lot - I paid school fees for both of them – and they have good jobs - I don't have a good job (laughs). They have got good jobs… but those one they are - the one my daughters aunt – my aunts daughter and my brother…they are doing well now and they are very kind to me…(laughs).

5.3. PATTERNS EMERGING FROM THE PARTICIPANTS' LIFE STORIES

5.3.1. The belief that strength develops from surviving previous hardship

One of the most striking features of these women's stories is their belief that they have developed strength and coping resources by having survived previous hardship. Many of them have made sense of their childhoods and previous difficult experience by framing it in their minds as having made them strong. N explains: "…I think to grew up suffering…others in my family gave up – we have no father, so what- so I knew I must do it by myself… that is why when I find out I am HIV…I was thinking this is a minor thing…and I still have hope…". This description elicits the notion of having to become a precociously responsible and independent child in order to survive difficult circumstances and a self-sufficiency that includes determination and hope for something better. E's description of her childhood and her response to this also speaks of quiet determination and a sense of needing to help her mother:

> I can say…I've been strong all along since I grow…because we used to grow in a poor family…not to say it was poor but to the fact that drinking parents…my father was drinking, my mother was drinking…then my father was working…I think now he should have been a richer person, but he was an outgoing person…he didn't care if we were there or not…then when he would get the salary and comes with it in the house…he would share it and then go with his money to drink…then he come back later and want the money he shared with my mum back…he want it back to buy drink and cigarettes…it was a difficult thing…when you have R2 you know you have to buy some grocery for my mother…so I grow like that and learning from the child that I had from a young age without a father…I say I don't have to sleep like this…I have to pull up my socks because there is nothing that can help me now…

While E's comment shows how she understands that her difficult childhood made her'strong all along', S' comment also relays a belief that her childhood molded her into the person that she is today and that her independence as a child is what makes her able to look after herself and her children alone:

> …I think so…when I was in high school doing grade 11, I was working in the holidays, temporary jobs, with my older sister…we were starting to be independent…so I started to be independent… Uh…I don't know how to say it…I think if you are independent…you can survive on your own without… without being dependent to somebody else…I think the way I grew up molded me up to this stage…because even now I am surviving alone…I am having three kids. I am taking care of them without any help…and my brothers and my mum and dad…but I am not forced to support them because I am married but when I am having money I send to them…not every month…

The strength that many of the women refer to is the ability to be independent and look after themselves. E relates not having to ask anyone for help to strength and she associates not having had support as a child to her belief today that independence is important:

> You know the thing that makes me strong again is that I am having everything on my own…I don't have to cry to somebody for anything…I have decided that even though I was suffering I was not a person to go to my aunt…my aunt is a person who is living with her own things…I didn't go there and ask her for things…I don't have school shoes…because she will be saying ja, when you are finished your school I will never be seeing you again…you will be on the street with your own money…ja, there was even the times…we used to get food at the school …free

food for the children who don't have no nothing at home…but sometimes there was no food at school…no bread or what…and then I had to go back home for lunch…in high school lunch was one hour…and sometimes I would get there and there would be nothing…so I would go back to school but I don't say nothing to my friends, hey I'm hungry, I don't have nothing…I just kept quiet…growing up like that…I didn't have any problem, I was just growing, it was just a thing on me…a simple thing…to stand up by myself…I would encourage other women to do that …not rely on a person…not even on the grant money…when they asked for the first time when I was bringing my son here…they ask me 'you, you don't want grant?' I say no…because when you put your money on a thing for something you didn't work for you will be stupid…you will not spend it the same as something you worked hard for…if you get it free you will be stupid…

M also relates strength to the ability to manage independently and look after herself and her children. She relates that the relationship she had with her mother was different to the relationship her sisters had with her mother, in that she felt that her mother treated her unfairly and expected her to look after the extended family, while her sisters were treated as children and looked after:

Interviewer: So you think that maybe what happened between you and your mum, you know, that she was so tough on you in the beginning, do you think that helped you to be stronger later?

Ja it did help me, especially the one year when my dad and my fiancee passed away. It did help me a lot. It did. You know. I could take care everything . Ja. I could still…for everything. My other sisters can't – even the one who is here

R relates her strength to having had to stand up to her alcoholic father when she was growing up. She regards the ability to speak out and stand up for herself as strength:

> Ja…it is because I speak too much…you know, I'm firm…if I don't like a thing I say you know what you are doing is wrong…the others couldn't do this with my father…you know, even my mom…but you know when I was angry and I thought ok I can't take this anymore then I would tell him what he was doing was wrong…uh…I think it was because they were too quiet…and I was not…even now…they are quiet and I am the one that is fighting…even in the hospital…the other people are just keeping quiet and I am the one saying hey, this is not right, you understand?

Many of the women also related stories about the fact that having survived the losses that being HIV-positive had caused, has made them stronger. C explains: "Ah…I think it is many things that I go through…that is why I am strong now…many things…first it is my husband who is passing away and then I am sick and then my child is getting sick…many things…".

5.3.2. Precocious responsibility and self-sufficiency

Many of the women's stories related a childhood that was shortened in that they had to care for younger siblings and assist their parents. This role of caretaking that began early on is continued today, with many of them financially supporting their siblings and parents. M describes how she assisted her father to put all her younger siblings through school: "…even when I came in joburg I used to, because I took my sister to school ….. all my sisters – I helped my father - they to go school".

For some of the women this caretaking role was a good experience and they felt supported by a parent, as can be seen in C's comment: "…I getting strong because I look after the younger children at home…and I loved them too much…my mother she loved me…". However, for others, the role was taken on out of necessity. M's following comment shows how she took on a caretaking role from a young age:

I was - I did my 'O' Level exams, then I got only three subjects and I ran away from home…didn't want to stay with my mum. Do you know we used to be an extended family…in a four house rooms, we could be maybe ten or twelve with uncles from my mum's side, aunts from my father's side…I was the elder…my mum wasn't home - I am from school…I have to cook and look after my father and my aunts daughter…who was, my aunt was here, so she lived with my dad…they were…seven years…you know how seven year olds are, they need their mums. (laughs) So I was the first one to wake up , boil water, I bath them, I clothe them, it was so crowded…I…when they are from school, they don't know how to put their socks - I had to find stockings for her .   I think growing up made me strong. Ja…ja I think growing up there made me strong – because we could see come home from school you get in the yard, its dirty…you have to start with the yard, because my dad…I would start with the yard, go inside, clean, cook…now I'm in high school cook…I finish maybe past eight…I'm tired…I cant even study I will say… OK, I will catch up in the morning…I will wake up at three and study…I can't… Ja with the aunts and uncles…they didn't care…I had to look after them…cook, do everything for them…these little one, my aunts daughter and my brother (laughs) they were a handful.   I would go to school, because it was a thirty minutes walk…I go to school ten past seven…I had to go with them, leave them at their school, proceed to my

school.   From school, I would cry they are dirty…you have to

bath them.

While M's comment reflects her immense sense of responsibility as a child, it also reflects a degree of resentment at having to take on this role and her desire to escape it, hence, her running away. N also describes a childhood where she felt she had no support and her need to develop a sense of independence. She also left home early:

I think it depends how you grew up…nobody gave the direction

when I was young…my mother passed away when I was

young…I was learning things by my neighbours…I think to grew

up suffering…others in my family gave up – we have no father,

so what- so I knew I must do it by myself…that's also why I

went overseas two days after my matric results…

E explains that her childhood entailed that she take on the role of caretaker in an emotional sense for her younger siblings. She describes comforting her siblings when her parents would fight: "Too much because…huh…I had to be brave…even now, I'm not just a crying person…I had to comfort all the people who were crying…keep quiet, don't cry…it will end…like that…"

5.3.3. Protective attachments

Many of the women described poor childhoods that involved absent, alcoholic and sometimes, even abusive parents. However, the vast majority of the women described having had a good relationship with one parental figure despite having a difficult relationship with the other. M describes a difficult relationship with her mother, feeling that her mother favoured her sisters, but she explains feeling that she was her father's favourite and how she felt she could talk to him. He was in fact the first person in her family that she told that she was HIV-positive:

When I was little we stayed with my mother but when I was going to grade 1 I was the first one to go to stay with my dad in town. He loved me. I was in grade one he cooked for me in the morning, left food on top of the stove and he used to tell me 'when you come back from school – you eat' I was short ja, I would take my food, eat, put away the dishes until I was in grade 4 - I was alone with my dad. And my dad, he was cheeky – but he didn't like hitting. But my mum shooo everything she picked up…(laughs). So with my dad I thought he understood me, but my mum, those times I even thought she doesn't like me when I asked my dad he said no, your mother likes you – you are the first born everything is for over you. Everything at home, we were five - when she is calling someone, she will call me – always I must come now - must come and help. Me…if we keep quiet all of us, then she is cross…she is cross with me, then I thought, oh my mother doesn't love me. With my dad, if you make a mess, he will warn you one, two, then third time maybe he will hit you, but I didn't see a chance being smacked by her…ja… I didn't communicate well with my mum, but my other sisters you could find them sitting in the lounge talking - I couldn't do that, I couldn't (laughs). They could talk, a long talk, laugh, everything…it tells you a lot, because at home I never remember every day sitting down with my mum, talking…I was so scared of her – my mum she was a vegetable farmer, ne, she used to farm and the excess she sold so when, she used to stay at home a lot - and now it's school holidays, I have to go home – oooh…those were the tough old days and then I was big, my dad asked who is going to remain in the house…I was the one…I didn't want to go home. When she comes to

town…eish…I love to go in school and stay and study after hours…I was so scared of her…

Nearly all of the women described having felt loved and close to at least one parent. N described being close to her mother up until her mother's death when N was 11 years old. She then describes having to develop other attachments: "…my mother passed away when I was young…I was learning things by my neighbours…"

5.3.4. High levels of insight

All of the women's stories suggested that they had thought about or processed their experiences in their lives. Most of them displayed the ability to consider other sides of the story and a sense of empathy for others was evident. The following comment from M suggests that she has managed to process some of the difficult feelings around her relationship with her mother and that she is able to still appreciate the good that she could experience in her relationship with her mother:

> …so when I sent money, sending money for her [her mother]
> then she would divert my money to my other sisters - I felt hurt.
> Why is she doing this… but when I get pregnant, she came, she
> help me with my daughter then I started working and by the time
> she passed away, we were starting to get along (laughing)

M then went on to speak about how the fact that her mother treated her differently allows her to be independent and look after herself: "Towards me, I thought towards to me cause with others…my sister…it was different because she was the last one…ja…even now my sisters are too lazy do you know they are so lazy they can't even do anything - my back is sore, my feet are sore - because of my mum. I can do anything (laughs)". Her next comment then revealed that she had thought a lot about why she had been treated differently and how it must have been for her parents:

Interviewer: It sounds like it was very difficult growing up…your mom and dad had quite a lot of expectations?

Ja…they didn't plan their life like that. Mum staying there, dad this side - who is going to look after the kids?...Ja ah shoo…my mum stayed in the rural areas a lot - my dad travelled a lot…

In the stories of these women, the fact that they had thought about their own childhoods and processed the experiences was evident in the fact that they had decided to parent their own children differently.   R talks about her abusive father and the effects that his behaviour had on her:

…at the times that I did stand up to him…it was just because I thought that I could make him stop beating my mother or my brother…but it didn't…he just kept beating…I often thought that maybe if I didn't have a child maybe I could have been as far as he wanted me to be and he would have been happier with me…but then later, I just thought that it was his drinking…the way he brought us up was like…he didn't want us to go out and explore, you understand, and I thought that is why I went out…but yes, he was very overprotective…even now…I think loving someone too much is dangerous…because then you don't let them live their own life…you know, this mark on my head was from a time my father beat me…everybody thinks it is a birthmark but it isn't…but we all have scars in some way…I suppose…I try to be different for my daughter, you know…but now I think I understand what my father wanted for me…

This comment shows how she is able to empathize with her father, despite the fact that he was abusive. S also explains how due to the fact that there was no open communication with her parents when she was growing up, she has changed this with her own children: "(laughs) ja…you know, the way we were raised there was no open communication…I have it with my children because it teaches them how to protect themselves…"

5.4. CONCLUSION

This chapter aimed to introduce the participants of the study and provide some context to their experiences of discovering their HIV-positive status. The stories all involve hardship and loss and the patterns that emerged from their stories relating to their beliefs about their strength seemed to be associated in their minds with having survived previous losses. The majority of the women described experiences of having had to become prematurely independent and in many cases involved taking on a caretaker role for their younger siblings and sometimes even for their parents. Many of the stories showed that these caretaker roles play an important role in the lives of these women and despite their own HIV-positive status, that these roles are maintained to this day, although in some cases, in a different form. Overall, the stories reflect extremely difficult experiences overcome with sensitivity and insight.

CHAPTER SIX

RESULTS OF THE STUDY

In the middle of the journey of our life, I came to myself within a dark wood where the straight way was lost. Ah, how hard it is to tell of that wood, savage and harsh and dense, the thought of which renews my fear. So bitter is it that death is hardly more.

Dante Alighieri – The Divine Comedy

6.1. INTRODUCTION

In this chapter the results of the study are presented. They are discussed under six main themes, one of which is elaborated and discussed under a further seven sub-themes.   One of the six main themes is considered to be a meta-theme and although it occurred in the interviews as a theme in its own right, all the other themes can be integrated into it. Very little theory is integrated at this stage in order for the reporting of the data to remain as true to the raw data as possible, however, due to the nature of qualitative analysis, some interpretation by the author was unavoidable. Ten women were interviewed and although the exact numbers of participants who shared a certain experience or opinion are not specified, terms such as all (10), most (more than 8), many (more than 5), half (5), some (3-4), a few (2) or one (1) are used to give a guideline as to how many women shared a particular theme.

6.2. THEMES AND SUBTHEMES EMERGING FROM THE DATA: COPING ACCORDING TO THE PARTICIPANTS

When embarking on this study, one of the major problems with finding participants who fell into the category of 'HIV positive women who are coping', was the definition of coping, and according to whom would these women be coping. Hence, it was decided at the outset of this study, in line with the tenets of qualitative research, that the definition of coping used by the study would include the participants' thoughts, ideas and feelings around coping. It was also decided that only women who felt that they were coping would be included in the study. What follows here is a discussion of coping according to the participants of the study.

In order to explore these women's ideas around coping with HIV, it is important for us to gain a clearer picture of what it is that these women are trying to cope with i.e. the areas

of their lives impacted by an HIV positive diagnosis. These themes became evident throughout the interviews and are inextricably linked to the participants' processes of coping i.e. the areas of their lives with which they are trying to cope influence how they cope with them. Hence, the 'what' and the 'how' will be discussed simultaneously.

The areas of their lives with which these women feel they trying to cope that emerged from the interviews were loss of or threat of loss. This loss included: their happiness or their ability to be happy; their health and even their lives; their financial stability; their sense of self, their roles or purpose and their relationships to others; and their sense of security and meaning in the future.

6.2.1. Coping with loss of happiness and the ability to feel happy

As described in the previous chapter, all of the women interviewed spoke about a time after diagnosis where they felt shocked, sad, angry, afraid and overwhelmed. In the first few weeks following diagnosis, none of them felt as if they were coping. M stated: "It was horrible. I was angry and I didn't know what to do…I didn't even tell my fiancé." R related her experience of the first few weeks after she found out her status: "I don't know…how I coped…I don't know, really…because sometimes when I was alone I would just cry a lot…a lot…". After a period of time, the women felt as if they began to cope and so, for many of the women interviewed, coping was seen as a state of mind or a subjective feeling that they are strong and managing and able to feel happy again.

T stated: "Yes…I think I am coping…because I feel fine with everything…I am accepting who I am…". N commented: "N Yes, I am…definitely I am coping…the things that I used to feel before… when I heard that I am HIV positive…I think that I have overcome so many things…".

The participants' comments also implied that this feeling of coping is a choice. Most participants felt that by making the choice to live and cope and survive and be happy,

they could have an impact on the external things e.g. their health. R stated:

> …but it is also something like, you know, handling it…that these
> other people, they just can't take it…they think…I've got
> HIV…I'm going to die. And it also the family, you know if they
> can't handle it. With me, at first I thought I was the only one in
> my family, but then I found out about my brother…he was also
> positive…but he passed away…it was because he didn't want to
> accept it…he was ashamed and just got sicker and wouldn't go to
> the doctor…and so he died. I decided that I was not going to die
> of this HIV…I am not going to get sick…I will not get thin and I
> will not get grey…

R believes that her decision to accept her status and cope and survive is what has kept her
alive with HIV for 14 years. This implies that believing she is coping and healthy is
something she can choose. K's opinion is that not accepting an HIV positive status is
what caused a friend of hers to give up and die, and states that this event is what helped
her to make the decision to accept her status and cope with it:

> …so it's when I took my test and found out that I am HIV
> positive too, ja…because there is no way, eish, he is going to be
> HIV positive at thirteen year – so I thought maybe it is…maybe
> from me – but – ja but firstly I had to get our results - it took me
> like a month to accept – but eventually, I did accept…especially,
> like, ah a friend of mine, he passed away because he couldn't –
> so I've learnt about HIV, and especially like most people I
> cannot…by not accepting – they will get fear – the only thing is
> to accept. Ja, then everything just goes smoothly…

Many of the participants also expressed the feeling of coping as being related to regaining the ability to feel positive emotions again. M stated:

> I told him that I was in difficult times. He always encouraged me when he sees me at work, I'm down, he comes and talks to me - I started laughing – I wasn't laughing before…I was always quiet…scared and angry – then everything started to look up…"

P referred to this feeling of coping as the sense that: "…I am living a life just like any other normal people…", while E referred to it as: "…just that I am strong…I learned to be quiet and think for myself…

These comments show that coping also implies a sense of normality and being like others as well as a sense of autonomy, self-reliance and independence.

6.2.2. Coping with loss of physical health and possibility of death

P's comment shows the link between physical health and coping in many of the participants' minds: "…it is like I have accepted that I am HIV positive…I am dealing with it…and as long as I am not getting sick or stressed by it…I am living a life just like any other normal people…". T's comment also supports the idea that physical health and psychological coping are interrelated: "…because now I am strong…at that time I was very weak…I was weighing 54 kgs…once I was on treatment I started gaining and then I was strong…".

Many of the women describe fear and depression accompanying times they have been very ill due to both the physical and emotional pain and the reality of death that the illness evokes, as O's account of her hospitalization shows:

> I was thinking that I was going to die…I was saying all the time
> to the doctors…just let me die…and the doctors kept asking me,
> no, why do you want to die…the pain was bad…and I was
> thinking I am very sick, it is better for me just to die…I am tired
> of being sick…to die is better than to be alive…but then I got
> better (laughs)…and then I went home and I started to pick
> up…then I was thinking it is better to be alive (laughs)…

N recalled a similar experience:

> I was in hospital…for 3 weeks having meningitis…but here I am
> today…I'm fine…just be strong, just be positive that you can
> fight this disease…I fought it…I was 24 [kgs]…I lost weight…I
> was thin, thin, I couldn't eat and I had this headache – it was
> terrible…but after 3, 4 weeks I accepted it…they were
> explaining everything to me, how the tablets works…during the
> process of healing when I was sick, I saw that it helps…because I
> was taking the medication…I didn't have even side effects…my
> positive side effects was that I was eating too much…I couldn't
> eat for 2 months…but I was eating like nobody's business…

However, after recovering from illness which entailed having to face the fear of physical pain and their own mortality, many of the women describe gaining a sense of strength and hope. O also described how seeing extremely ill people recover gave her hope and how she encourages other women at the clinic by telling them her story of how she was so ill all her finger nails just dropped out and how when she shows them how her finger nails have grown back they are encouraged:

> …someone will tell you, you know me…I was very sick I
> couldn't eat and I was lying in the hospital and I was nearly
> dead…and then you are seeing her she is healthy and

strong…and then I am thinking I can be like her…ja, when we are at the clinics we talk…like me…I was having all my nails out…and at the clinic I am telling people I was not having all these nails and look now they are all back…(laughs)…and they all say…oh…

T recounted a similar experience:

…most of the times I was feeling lonely and thinking that I am dying…but then at the time that I started to come here and join the other ladies I see that there are many other people outside with this sickness…it's helping because most of them if they are coming to that place they are shocked, but after that I am seeing them starting to be happy and talk with others because others when they are first disclosed they are crying too much but then they are talking with the others…they see that they are coping and it helps them…some of the other ladies are telling me that when they first come here 'I was very sick', you see 'I was very, very sick' and now I am better…

T also explained how after she gained hope by hearing others' stories of recovery, she began to use her story to try to assist others:

…even this lady at work…she was very sick and thin…I was telling her that she needs to go to the hospital and get treatment…I was telling her…you see me…I was very sick but now I am strong……I am feeling proud to help them…ja, at the first when I was finding out I was feeling ashamed for the HIV…what the people would think…but now I talk a lot…

6.2.3. Coping with the loss of financial stability

For many of the women, their illness and the loss of their partners left them financially ruined. Many of them state that they felt they were at last coping when they felt financially stable again. K spoke about losing her job after her boyfriend had passed away and the difficulties she experienced supporting her son after this:

> Ja…because I have been... actually I was working, I was working our company was liquidated…last year May…ja it was liquidated -so since I have been not to work you know, but I have been looking for the work since then. Ja…it was like now financially it's difficult for us because like at school last year…I can say last year I couldn't even afford to pay the school fees, you know, and then even this year, even like, they told me not to bring him back to school until I manage to pay them the other one you know, because I've been trying to get a grant for him…I went and spoke to the principal I said I will try…I'll try to pay…

M recounts her experience after her fiancé died:

> …what happened was so bad - it only took him a week…couldn't walk again so I took him to…I asked the uncle to take him home - we were maybe six months in arrears on rent so the landlord took everything, everything - so I went home, I took leave…apart from only two days, he passed away so when I came back I had nothing, I only had my daughter, my work…there were temps - you wait three weeks relieving someone, you wait three weeks then there is nothing - you work when you have something - and now you have to parent, pay school fees, buy food, that time it was…I worked three weeks,

three weeks. Then there was another woman who said she wants someone for four months. When I was there then she said she want me permanent - then I can pay my daughter's school fees, new uniforms, we can eat. Then she was…when I came here, they helped me, I saw direction. I started to cope (laughs) yeah…there is something she [her daughter] wants, she doesn't get - only her mother's love…that what she gets and that's what I told her. I told her I can give you my love, but, plenty things you were getting when you father was alive - I can't…the other day she said to my sister – 'its better now' because we moved to Soweto, and we've got a room there, I'm paying less, she goes to Soweto school, we pay less than here - now some other things she gets now – she says 'mmmm aunty, we now coping' (laughs)

S recalls a similar experience after the death of her husband:

…I had a lot of anger after his death…because I experienced a lot of problems…about the bond…(starts crying)…after his death I experienced a lot of problems with his bond, because he bought a house and then the insurance refused to pay…so I run up and down…because I needed the house and my children need the house…so I was prepared to take over the bond, but the bank was not responding to me…for nearly one year and six months…and I was living in fear that the bank was going to come and take me and my children out of the house…so in May I started paying money into his bond without any agreement with the bank…because I was so scared the bank would take us out of the house…but now my lawyer has made an agreement with bank…I signed and I took the house and I pay the bond…I'm not so scared now…there was anger because now I was suffering…but now things are better…

Hence, for many of the women, HIV and the loss of partners who provided income left them alone and financially desperate. For many, this was an extremely overwhelming and frightening experience, especially due to the fact that they had children to support. For some, like M, it meant starting again, and for others, like S, it meant fighting battles with banks and insurance companies at a time when they felt vulnerable. It is evident though, that for most of the women, the experience of becoming gradually more financially stable signaled a sense of coping better.

6.2.4. Coping with the impact of an HIV positive diagnosis on sense of self, roles and relationships

A number of sub-themes emerged under this theme, namely: resolving grief over the loss of loved ones; overcoming a fear of the stigma and shame attached to HIV/AIDS; being able to disclose and talk about their status; accepting support from others; a fear of hurting family members with the news of their status; fulfilling of caretaker roles; the importance of independence and self-sufficiency; and the avoidance of pity from others.

6.2.4.1. Coping is resolving the loss of loved ones

It is important to note that for most of these women, the process of coming to terms with an HIV positive diagnosis is set against the context of multiple losses. Most of the women described having lost one or more members of their family, many to AIDS, during the time that they were trying to deal with their own status. For many of the women, having to see and watch other HIV positive people get sick, thin and unable to walk and then eventually die, increased their feelings of anxiety and fear about their own deaths. E reported: "Sometimes I am asking myself when it comes to this point, what am I going to do…why can I not die when I come to that position of AIDS…I don't want to suffer…because I have seen so many people suffering because of this sickness…". R

stated: "…you know, like when I am alone I can feel it come…it was like the feeling I have when I see someone really sick…and I feel scared…and it was hard to be alone…". O also commented:

> Ja, it took some time…because when you are thinking about this dying thing…you know, it's bad…the first thing that comes to your mind is that you are going to die…I'm going to die…I'm going to get thin, thin, thin and the thin, thin hair…those pictures, when it comes on those things…what are the people going to say to me…laugh at me…I'm not scared of dying…I'm scared of way of dying…maybe I will get too much sick and then die…can't even do anything for yourself…takes a long time…but then the time I was very sick with the meningitis…I survived it…

For some of the women, the losses of loved ones were overwhelming and left them feeling more isolated and disconnected. M stated, after the loss of her husband and her father within 3 months of each other: "…that was a hard year of my life…it was like drifting…it wasn't me walking. I remember I collapsed on the train going to work one day - it was hard, very hard…". For others the losses left them with feelings of guilt, that they had survived and had not been able to help their loved ones. After the death of her husband, S reported: "…and he didn't survive…I felt bad by that time…because I failed…I failed to help him…I managed to help myself and my child…but I didn't hide anything, I told him…I said he must go to Helen Joseph and get treatment…". R reported:

> You know, it is when I see the very sick people at Helen Joseph and when I see my friends get sick…this frustrates me a lot…uh…it is at these times that I am questioning myself, you know, how come these people are sick and I am still healthy after all this time? It is hard when I am walking tall and the next

person next to me is very sick and they don't want to talk about it…I try to find a way to reach them…I tell myself that I must try…but if I can't it makes me very sad…

After the death of her brother R reported:

> …then I found out about my brother…he was also positive…but he passed away…it was because he didn't want to accept it…he was ashamed and just got sicker and wouldn't go to the doctor…and so he died…a part of me does feel guilty because…I tried to save him but I couldn't and he passed away…you understand? I was thinking maybe if I had done things different, if I could have been hard enough…maybe he could have been here today…but he's gone and there's nothing I can do about it. I decided that I was not going to die of this HIV…I am not going to get sick…I will not get thin and I will not get grey.

R's comment also shows how the deaths of those close to many of these women also awakened a determination in them to live and to stay healthy in spite of HIV. The women who describe this experience also relate how the deaths of friends or family members were related to the fact that these people could not accept their status, and that this motivated the participants to face their status and accept it. K related how a friend of hers passed away because he couldn't accept his status:

> …but firstly I had to get our results - it took me like a month to accept – but eventually, I did accept…especially, like, ah a friend of mine, he passed away because he couldn't…so I've learnt about HIV, and especially like most people I cannot…by not accepting – they will get fear – the only thing is to accept.

P also related how she tried to help a friend of hers with HIV and how difficult it was for her to watch her friend give up on life:

>…it's like there was this other guy, we go to church together…and even though he has not said he is HIV positive but he has a lot of symptoms…and then he was admitted…I went to visit him…I never said shame…I just told him…you must eat, drink a lot of water, do this and do this…you must walk, get out of bed, take a walk…5 minutes and then come back…I never said…and then when he said to me…aai, I am dying…I said, you are not dying, aai, you are not going to die. Then he said sing for me…I said why…and he says so I can rest in peace…and I said, no you can sing for yourself…it's that I don't want to…you know it is only when I am out that I feel very pity that ooh, he is very sick…but I am not going to say that to him…when I am with that somebody I don't want to show that person that he is very sick and that he is going to die…now, he has been taken to his family at home and his wife said that he is very sick…at Baragwanath they did nothing to help him…now he can't even walk…you know at one time my CD4 count was very low, very low…34…and I could feel that I was very sick…even today…I think…God is great…I could have died…Helen Joseph helped me a lot…

M also recalled supporting her sister, who is also HIV positive, after the death of her sister's partner: "Ja , she was very lonely, she was saying 'Oh, how, why can't I die too' but I don't think that the way for her…you can't say I have to die too when someone I love died,   you won't die, you will be sick and that is not nice – all the pain…".

Some of the participants reported feeling ambivalent toward life after the death of their partners. C reported feeling very angry that God had taken her husband before her.

However, she explained dreams that she had had after his death and how these dreams highlighted her will to live despite the loss of her husband:

> The first dreams…I have them when my husband passed away…and then my husband in the dream he was in my house and he is there to call me…C, I want you…ah…that time I just feel sad…because in the dream it is like he is still alive…and then I wake up and then I am sad…you know the old people they tell me that sometimes when a husband or a wife dies then they come back to take the other one…(laughs)…I was scared…

C's dream also highlights the role of traditional beliefs in coping with loss and shows the perhaps more unconscious grieving processes. P also recalled two dreams that she had after her father passed away, while she was in hospital:

> …at home we do believe in ancestors…the way we grew up…with my father's family slaughtering the goats, making the Zulu beer…they believe in ancestors…but God comes first…you know, when I was sick in the hospital, my feet were very painful and swollen, so much that I couldn't walk. As my father died when I was in the hospital…and then I had a dream that there was a man, I couldn't really see him, he was at my bed and he was massaging my feet and when I woke up my feet were better and I can be able even to walk… and then about a month later when I was still in the hospital I had another dream but a man came again in my dream, I couldn't see his face but he was wearing a coat, a long one…and it was my father's coat…and he said that I will get better…I must wake up now and pray and then I will get better…so, I woke up and then I phoned my sister and I told her about what I had dreamed and I asked her what I should do and she said that I must do as the man said and I must pray, so I did and then I got better

(laughs)…

For many of the participants, feelings of loss were also expressed around unborn children that they had taken the decision not to have. While R chose to terminate a pregnancy, E and O spoke about taking a decision with their partners not to have further children due to their HIV positive status. O explained: "…my husband and me talked about it and we thought that because we are HIV, we are not going to have another child…we have the one…it was sad…I thought I was going to have another chance…you know, another baby…".

Coping with loss and especially with financial difficulties after the loss of a partner, caused many of the women to confront the inevitability of their own deaths and make provision for those they will leave behind. S explained:

> Ah…I am not scared…I have been organizing life cover, you know the one for people with HIV…so that my children can pay up the bond…I think my diagnosis made me think differently about some things…I have had to think and plan for the future…I have had to be strong for my children…

For many of the participants, coping with their HIV positive status has also entailed coping with the loss of partners, family members, friends and even unborn children. While the periods of illness and deaths of loved ones have increased the participants' fears around their own deaths, coping with these losses and resolving their grief has allowed many of them to appreciate the time they still have with loved ones, reinforced their own will to survive and remain healthy and assisted them to confront the reality of their own deaths with dignity.

6.2.4.2. Coping is the ability to move through fear and shame of stigma and discrimination

For all of the participants, a part of their process of coping with HIV was coming to terms with the stigma around HIV and their fears around being discriminated against. Many of the participants reported feeling ashamed of their status, of how they had contracted it and afraid of what other people would think and say about them. C spoke about her fears when she first discovered her HIV status. It was during the time her husband was dying of AIDS:

> I was scared the people will be seeing me going to the clinic all the days and then they will be saying HIV…and at that time the people were saying HIV…it was a shame for me…even me I was asking why I get HIV…it was bad at that time…it was hard…how did my husband get the HIV?

> Interviewer: It is a hard question…

> Yes…maybe only God he knows…

> Interviewer: What do you think people were thinking?

> People came to my house and they saw my husband and how he was sick…like my pastor...maybe they think me too I am HIV…in the first I was very sad…but now I am not to care…because there is a lot of people with HIV…but they won't to tell you…but I am still keeping it a secret…you know the black people…they talk…

S stated:

> You know to keep a secret, it is a burden…like with my friend who I haven't told…it is a burden, but there will come a time when I am ready…because I don't want to carry anything on my

shoulders…I want to feel light…I don't want to carry anything…it is also that when there are no secrets you feel accepted…they don't judge me…you know, like some people judge, like if I am using this cup then other people don't want to use the cup, it will hurt me…but then also…it is hard to just tell a stranger…you need to know the person first before you can tell them…you need to see what kind of a person is this?

S's comment highlights the pain that these women anticipate they will feel if people reject them because of their status. M's comment about her boss and the reason she has not disclosed her status to him also illustrates this fear:

Oh not that one ooooh…if you can hear him the way he talks. He is coward, he is big, he is rude. Ja…you see…he doesn't respect women. Then later on you tell him that I am HIV…eee…I don't think he will drink your cup of tea that one he is so stubborn…so arrogant all the words…

S's comment above also shows how important it is to these women to learn who they can trust and disclose their status to and who they shouldn't tell. E's comment shows how conversations with others that reveal their attitudes towards HIV are often the way they judge who to tell:

…I don't go anywhere, I don't party…the thing is I don't visit the friend…even the neighbour…I go there when there is problems…but I don't go there and just sit for 2 hours…because the thing I learned from my neighbour is that when I was sitting there…he used to say 'ay, you know these people with HIV…AIDS is doing what, what, what'…I was thinking in my mind, this is a wrong person…I don't have to sit with this person…when she discovers that I am HIV positive, she will be

going out again and speaking to other people things about me…

E's comment also highlights the fear these women have that if they tell an untrustworthy person their status, they will be gossiped about and the knowledge of their status will be spread around the community. Conversation with O also showed this fear of having one's status 'talked about' and revealed the pain that these women experience keeping their status a secret and listening to others speak in derogatory terms about people with HIV:

> …it will let people start saying I am HIV…maybe if people know they will be talk, talk, talk…you see, they don't say you've got HIV, they say you've got three words and the words are starting to eat her…
>
> Interviewer: And what would this mean?
>
> Ah, when people are saying the words are eating her…and the people I work with they see someone who is getting thin, they are talking…and they are saying 'ah, if I was HIV I would hang myself' and then they are saying no, you know those people who are sleeping there and there and then in the end they are getting their results and they are three words…I am saying no, it is not like that…but they are saying yes, it is like that…you see him, at first he was fat and now he was getting thin…three words are eating him…in three years he will be gone…they are saying that…
>
> Interviewer: So there is a big fear about HIV?
>
> Yes, they are saying, you know if you are getting a child who is HIV from birth…in 15…or maybe to 18 years they will die…and then I am thinking ay, is this true?

Interviewer: It must be painful for you when the people are talking about this?

Yes, it is painful to me…but I am not saying anything to them…when they are laughing…I am laughing with them…I accepted it and that is what makes me strong…and when I see other people doing well with this thing and I am seeing that I am not alone with this…

O also spoke about an experience she had at the clinic that illustrates the fear that these women live in. She describes seeing someone from her work at the clinic and being very afraid that this person would see her in the HIV queue and then tell others at work:

…you know, the one time when I was at the clinic I saw this one lady that I work with…she was not my friend, I just know her from working…and she was sitting on the other side, you know where the people sit who are just getting normal sick…and I was saying to the lady next to me, ah, you see that woman, I know her from work, she is going to tell the others at work that O is having a big file at Witkoppen…we have big files there…and my friend said, don't worry, maybe she is also sick…and I was hiding like this…but then the following month I see her again and I greeted her and I just kept quiet…and then the following month I see her again and she is also having a big file same like me (laughs)…and I said 'Hi, how are you?' (laughs)…and then we spoke and I told her that I saw her before and she said, ja, I also saw you… (laughs) …and then the following month she was sitting next to me at the clinic…and then I told my friends, you see, this was the girl I was telling you about from work…and they were saying…you see, the people on the other side…one day you find them this side…

For many of the women it appears that a part of their coping with the stigma and shame around HIV is about finding other HIV positive people to talk to and feel a sense of belonging. People who discriminate against them, of whom they are afraid, are seen as worse off for not knowing their status.

6.2.4.3. Coping is the ability to talk about their HIV positive status

For many of the participants, finding their voice and being able to help others helped them to find meaning in their experience and move past the shame they felt. T describes: "…I am feeling proud to help them…ja, at the first when I was finding out I was feeling ashamed for the HIV…what the people would think…but now I talk a lot…". For many of the women the process of dealing with the shame associated with their status is a step towards acceptance and coping. O's advice to other HIV positive women was: "…they must accept it…they are not the first ones and they are not the last ones…don't be ashamed…".

The stigma associated with HIV seems to have contributed to each woman's struggle to accept her status and to disclose her status in order to access support.

As discussed in the previous chapter, many of the participants reported feeling very alone after finding out their positive status. They felt that soon after finding out their status, it was difficult to talk about it. They described a period of time where they felt they were not coping and chose to keep their status a secret. Many of the participants described how they isolated themselves and cried a lot when they were alone. Slowly though, as they felt the need arose, they spoke about starting to tell various people they trusted. Many of the women interviewed spoke about disclosure as being a sign that they have accepted their status and are able to cope. S stated:

Ja…yes…I think I am coping with my disease…I don't have a

problem because I talk about it…my supervisor knows, my colleagues, the counselors, the doctors, they know, everybody I work with they know about it…even my family…but there are certain members of the family…I didn't tell my parents, its only my sisters who knows and my children knows about it…

Many of the women spoke about the importance of being able to talk about their status, in that it allows them to share their worries. Many of the participants made the link between keeping their worries to themselves and becoming ill from the strain. M explained this:

Ja , I think so, you can't hold everything inside …sometimes when you burst, it's not good. Ja… always think… when you are alone you think about it if you are not telling anyone, you see? When I'm sick then you going to start asking, because everyone….now you are sick, ne, then they start asking, so it's better to have someone, especially family to talk…

S agreed with M and explained how not talking leaves her feeling sad and stressed and how this can lead to becoming sick:

You know if you hide things you get sick…you get sick…stress makes you sick…naturally I am a person who likes to talk…that is why I don't hide even my status from the counselors… I don't want to get sick. You know I feel energetic and alive…(laughs) ah…the thing is…I don't …I don't want to be sad, I want to be always happy…that is why if anything stresses me…I talk about it then I am happy and I feel better…if I keep it in I can become sick…

They also spoke about how being able to joke and make light of the situation eased their minds and helped them to feel normal and sometimes even helped them to forget their

pain. O described: "…sometimes…I make jokes sometimes…when you laugh and create jokes you forget everything for a while…". R also explained:

> Uh…you know…it was hard at that time…everyone was afraid of HIV and you would hear them talking about HIV and saying bad things about people with HIV…and it would hurt me…and eventually I just said…you know, not telling people about my HIV is eating me…you know, like when I am alone I can feel it come…it was like the feeling I have when I see someone really sick…and I feel scared…and it was hard to be alone…but then I did tell them and now we make jokes…you know…you know, it relieves you…you know, to joke…sometimes I even forget my tablets when I am at work and then it is ten o'clock and someone will go over the loudspeaker of the shop and say, 'R, R'…and then we have some funny words that they use so that I can know what they are talking about and then I remember…'R, R, it is time blah, blah, blah and then I am oh, I must take my tablets…it really does help to have people around you who know because they can help you to remember…

R comment also suggests that being able to tell others their status allows them to access both practical and emotional support from others. S also explained that despite the difficulty of sharing her vulnerability with others, talking to others and accessing support helped her:

> …it was not easy to talk about it…I think I have accepted it, I can talk about it now…but it's through, I think it is through the support, the support of my family…my sisters, my children, my fellow colleagues and my supervisor…they are very supportive…they are non-judgemental, I can say they have

accepted that there is such a problem…even if I need to go for my appointments there is no problem…I know I can go…

R described how her decision to tell her family and work colleagues her status enabled her to take care of herself and her daughter more easily. It also allowed her to access assistance in the raising of her daughter:

> …you know, it was 8 years doing everything on my own, with no-one knowing…but now, I decided that I needed my family to know, because what happens if I am not at home, if I am outside and my child needs to take her medication. So now, if I am not there, my parents they are there…I decided that they must know… and I also decided that I must be open with the people at work…because of all the doctor's appointments between me and my daughter… like now, when I am not at home I don't worry anymore about my child not getting her tablets, now I know that someone else at home will give them to her.

O explained the emotional support and encouragement she gains from talking to other HIV positive women while they wait in line at the clinic for their medication:

> …then you can take it out…because they are also HIV positive and they tell me not to worry…ja, you can take it out of your heart…then you feel relieved…and they will tell you their ideas too…I support others and they support me…ay…I felt better…because when we are together we are talking…and then we are laughing…you join them and then we laugh…because at the clinic we get separated…those who are HIV and the others…and we are saying…ja, you see that line (laughs)…they don't even know their status, just relax…maybe we are better (laughs)…we know…ja, they are encouraging me…because the

others they are talking, they are saying shew…ja, you see that line, they are HIV…but maybe they are HIV and they don't know…(laughs)... because sometimes you forget, you forget, if you are alone you keep on thinking, shew, I have HIV, I am going to die…but when we are together we are talking, talking…then someone will say…no, you won't die…you see that lady on the tv, she has HIV for so long and she is healthy…maybe you can be healthy like her…

S also described gaining a great deal of emotional support from her supervisor after disclosing her HIV positive status to her:

Ja…but if am sad…the person I am open to…is my supervisor…she is the one who is there for me…the first time I was placed under her I told her about my situation…everything…even now everything that troubles me I will talk to her about it…I feel free to talk with her…she is like my mother in fact… (laughs)…one who can listen to me…she is the one who makes me strong…

P also described gaining emotional and practical support from family members she had disclosed to:

My child's aunty…even she is very supportive. She phones all the time…everytime, you know, like yesterday she phoned us…how are we?...like my sister, my younger sister…I am working with her in the salon…and when my child starts to cough…she tells me to go to the doctor or the clinic or she gets stuff from the pharmacy if it is not serious…even myself she sends to the doctor…

S also described the support she gets from her boyfriend and how this support is important in that she can talk with him about things she may not be able to discuss with other people she has disclosed to:

> …the father of my…my eldest daughter has come back…but a few months ago…not a long time…but I won't get married again…I told him my status the first day he came back…I told him I am HIV positive…I was thinking if he wants to run away he must go…but fortunately he didn't run away (laughs) …he just accepted it…he told me that he loved me even before…the thing that made us to break up was that he was young (laughs) you see, he was after me all along and I was running away because I was married to this other man…

> Interviewer: Do you find it helps you to have this man in your life?

> Ja…I need to be loved (laughs)…because there are other things you can't share with your children, you need somebody to share with…and there are other things I cannot share with [my supervisor] that I can tell him…

Half of the women spoke about reaching a stage where they felt so comfortable talking about their HIV positive status that they felt they could be a support to other women by disclosing their status to them and sharing their experiences with them. T explained:

> Ah…maybe because I laugh, even now…and I am too talkative…I like to get things out…my mother she is also talking too much…she is the one that taught me to talk and get things out…she was always talking and laughing…and people would visit to talk with her…she was also helping other people…she is

making me strong so I am coping with a lot…even me when I am by the line for the taxi or at the work…I am talking and managing to tell my status to some of the people…it helps to talk about HIV…even this lady at work…she was very sick and thin…I was telling her that she needs to go to the hospital and get treatment…I was telling her…you see me…I was very sick but now I am strong…I am feeling proud to help them…ja, at the first when I was finding out I was feeling ashamed for the HIV…what the people would think…but now I talk a lot…

R also described how she has found a way to support friends and encourage them to get tested and go for treatment by telling them her status and letting them see how healthy she is and how well she copes:

> …and it was like when I told people they didn't believe me because I look so healthy…it's like even now, when I am telling people that I have been HIV positive for ten years, no-one believes me. But now I am making a joke of it…I have friends who find out that they are HIV positive and I tell them, uh-uh, you know, I go to Helen Joseph to fetch my medication alone and I am not going to give anyone any, they must go themselves and take care of themselves…and I tell them that it not like they now have to separate themselves, they must enjoy every day of their lives…it is uplifting to be able to help other people…you know that they want to be like me. I tell them, just go to this doctor…my doctor has been seeing me for a long time now and I am friends with him…I can also phone him when I need help for my friends…he is a big support to me…you know, he sometimes says that I must teach his patients how to be like me…and sometimes when he is off he comes to the shopping centre where I work and we have lunch and

we laugh and these times I feel better and forget everything

In addition to all of the participants explaining that being able to talk about their status helps them to cope, it can be seen in may of their comment that it is not an easy thing to do. E stated:

> …but I think it will kill me…because keeping all those hurts inside of me…when they grow inside of me…one day I'll die…one day at a time…(laughs)…I don't think I carry them all the time…I only think of them when I am talking about them…I don't think of them when I am just sitting…

However, despite this difficulty, the participants talked about the importance of being able to talk about their HIV positive status. While some referred to talking as a means to easing the burden of worry that they carry, others emphasized the feeling of support gained from being able to share their status and share the responsibilities that come along with it e.g. seeing to their children's medical needs. Many talked about the benefits of feeling less alone, accepted and loved. Other benefits of talking that were mentioned were feeling more hopeful and encouraged.

6.2.4.4. Coping is being able to accept support

For all of the women who were interviewed, the support they received from their partners, family, friends, the church and the hospital staff was invaluable. All of the participants spoke about how support from one or more of these sources helped them to cope.

For many the primary source of support was their husbands. E spoke with gratitude about her husband and the fact that he accepted her positive status and the status of her son from a previous relationship: "The thing is that…I thank him…he's the quiet

person…he accepted my status together with my son whereas he is not the one who made that thing…". N also spoke about how after discovering her positive status, her husband changed his lifestyle and became more supportive towards her: "…he used to go out and perform and come around maybe 2 o'clock in the morning…but he changed and after performing he would come straight home…ah…he was supporting me…". During conversation with O, she explained in detail the significance of her relationship with her husband and the support he gave her:

> …we can talk nicely…even the time when I was sick…he was coming to the hospital every day…and then when I was the first one to take the medication…and he was always reminding me…
>
> Interviewer: Do you think this relationship…being married has helped you…?
>
> Ja…it's because he is supporting me…keeps on coming to me at the hospital every day…and telling me no, don't say that you want to die, you will be fine…but I was cheeky to him…I was insulting him (laughs)…but he keep on coming…even that I was insulting him (laughs)…
>
> Interviewer: What were you saying?
>
> (laughs) That he must leave me alone…that I must die…
>
> Interviewer: That was a hard time…you were angry…
>
> …ja…even my family was telling me that I am lucky…some men won't stand for a woman like you…because you were scary in the hospital…someone would run away…

Interviewer: so…it was important that he accepted that part of you?

…yes…he was strong…

While acceptance of their status by their partners is important to many of the women, many others spoke about how acceptance of their positive status by family, friends and work colleagues helped them to cope. R explained the importance of support from others:

> …coping is…I suppose...is stress, do I get stressed at times…and how I deal with it…and how long it affects me…normally I talk a lot, so when I am stressed, I talk a lot to my family and my friends who are supporting me…mainly my mother…or I go to church…

> Interviewer: So, you are saying that you cope through relationships with others?

> Yes…it is very important…because it shows that you are not alone…that there are people who care about you and will stand beside you no matter what…they are supporting you in everything…you understand? Even if you are sick and they are not sick…they feel what you are going through…when you cry, they cry with you and this shows you…ah, that I am not alone…

R's comment highlights how emotional support from others helped her to not feel alone. P spoke about how the support she received from her family helped her to feel normal again: "Ha…I think it helps me a lot because I am not always thinking about it…they take my mind off it and they take me as a usual person…they don't see any change…". M spoke about her cousin fulfilling a similar role for her:

> We were staying in a flat in Pimville - the cousin I was staying with…she didn't like to see me standing on the balcony, or quiet – no. She was supportive too…if I go to the balcony, she would come, if she was at home – get inside – let's talk, let's do this, do this…

Others emphasized the more practical benefits of social support. S explained how a supportive work environment has helped her to care for her medical needs and the medical needs of her child more easily:

> …I think I have accepted it, I can talk about it now…but it's through, I think it is through the support, the support of my family…my sisters, my children, my fellow colleagues and my supervisor…they are very supportive…they are non-judgemental, I can say they have accepted that there is such a problem…even if I need to go for my appointments there is no problem…I know I can go…and their attitude also…it is non-judgemental…they accepted that I am having such a problem…

C spoke about the support she received from her husband's employer after the death of her husband and how this woman helped her to get to the hospital and get tested:

> There was one lady…a white lady who works with my husband…after R is dying that lady she took me again to the doctor to take the blood again…she was like a mother to me…her name is Michelle…she comes sometimes to sit with me and talk with me like we are talking now…and crying with me sometimes…

O spoke about how the other HIV positive women at the clinic helped her to cope after she discovered her status: "…they support you…even if you cry, they say, no, don't cry, don't cry…ay…I felt better…because when we are together we are talking…and then we are laughing…you join them and then we laugh…". T also spoke about how support she received from other women at the clinic helped her to cope:

> Because I used to come here to the hospital for my appointments and I meet some other ladies, same like me…that is how I started to cope…it helped me a lot…because at home there…most of the times I was feeling lonely and thinking that I am dying…but then at the time that I started to come here and join the other ladies I see that there are many other people outside with this sickness… I think probably the best thing that changed that was coming here…I was seeing the other ladies who were saying that they had been on treatment for 7 years…others for 3 years or 2 years…so I see I can be like that…because now I am strong…at that time I was very weak…I was weighing 54 kgs…once I was on treatment I started gaining and then I was strong…ja…hope is very important…I got that here…

Many of the participants also highlighted the role of God and the church community in terms of the support they feel they received. N spoke about feeling that God has heard her and helped her and the hope that this gives her for the future: "Ah…all the things I have been asking for God has given me…so it gives me strength to believe that God can heal this thing in us…". S also commented that she feels God protects her: "…I am having incidences in my life when I felt like God listened and helped me…protected me…he hears my prayers and answers them…". E also commented on how she believes that the ancestors are a way to communicate with God and that she feels protection through this:

> …it is just when I pray I used to call God and call them, I grew

like that…I ask them where they are… to help me…the thing that I believe is that God is the creator and he created the ancestors…it is a process from God…and they help you…sometimes there can be something that is coming to your mind, don't go there because you will get hurt or what…

C spoke about support from other members of the church community and how this support helped her grieve for her husband and re-engage with life after her loss:

When I was suffering the people at the church they is supporting me …they come and talk to me about the bible and talk with me about my husband…I must let him go…they help me let go…and that white lady…after my husband dies she come to me and take me out sometimes…

M also spoke about receiving emotional and practical assistance from her church community and how this support helped her to stay positive:

I was sick that time, and then I get this bad cough and I think ah…now I am going. I told myself - think positive – think about my daughter…and church was helping…there were mothers, the women came to our room, they talked to us, they prayed, even parcels. And giving your heart to God, you see…(laughs)…you mustn't think negatively, ne, just think positively…something, somehow will help you…you won't be down…

Many of the women also spoke about receiving support from the hospital system. They spoke about the importance of counselling in helping them to cope. P stated: "…but the counseling here at Coronation and the support from my family helped me…". S also spoke about her experience with psychotherapy: "…I went to a psychologist at that time… she was guiding me where to go…that was how I survived…". R explained how

her relationships with hospital staff members and the emotional and practical support that she received from the hospital helped her to cope:

> …it feels like I have friends here [at the hospital] you understand...there is support…here I can get counseling and it feels like they made it like HIV is no longer a thing where you can die…they teach you that you just have to take care of yourself…eat healthy…which is something that I try to do…but not always…(laughs)…ja, we got a lot of support here…

Despite the fact that all the participants emphasized the importance of support from others in the process of coping, many of them also described the experience of gaining support as being extremely difficult. M stated:

> …it's very, very hard to be on your own…and you are thinking…if I get sick…where I get money to go to the doctor if I do, eish – that was a tight time…I wasn't used to begging someone, please can I have this, please can I have…there was a time that I had to, I had to…my mum was gone, my dad was gone, my sisters were at home…I was here…and she is always sick…when your daughter is sick…she needs money…so I came with her here [the hospital]…

E spoke about her decision to eventually tell her mother her positive status. She explained how hard it was for her to rely on others:

> …I said to myself, keeping quiet, even when I keep quiet it won't help me. I had to tell him [her mother]…because now I am on the second treatment…I didn't tell her all that, that they change the treatment and that they say this is the last treatment they can give

me…I was thinking what would happen when I am lying on the bed…she need to know…

Interviewer: So, you are hoping that when the time comes your mother will look after you?

Because she is the only one…I have got my aunts but I don't trust them…together they are 4 with my mum…but I don't trust them…the other one speaks too much…and the other one is always traveling around…and the other one, she has one child but she is not a caring person…I don't know whether they will change their mind when they see you are sick and come and help in the home with this and that… you rely on a person every time when you are sick…you don't get up yourself to get water…you will be looking for someone to bring it for you… I don't want to rely on people all the time for things like bring me water, help me to the kitchen…that is the thing that is making me to stand up…I don't want someone to work for me…I want to work for myself…I learned so that I have to stand up and that I must work hard…it is not easy for me to just sit down…

E's comment seems to highlight an area of difficulty that many of the women reported experiencing, which is that of accepting support and help from others. Many of the women seem to pride themselves on their ability to remain strong and independent and the HIV and associated physical illness, together with their worry about the welfare of their children, seems to force many of them to seek support from others.

6.2.4.5. Coping is being able to maintain a caretaker role

A theme that repeated very strongly throughout the interviews was that of the caretaker

role that many of the participants fulfill in their lives, whether it is a particular commitment to being an available parent for their children, financially supporting extended family or encouraging and supporting other HIV positive women.

The caretaker role that many of the participants take is seen in their attitudes towards their children. Many of the participants talked about being around for their children and their children being okay as being a part of coping. In fact, many of the women spoke about how their role as a mother helped them to cope. All of the participants reported worrying about who would look after their children if they died. O states: "…maybe even if I get sick first who is going to look after her [her daughter]…". This worry seemed to have motivated many of the participants to cope and stay strong and healthy for their children. K reports:

> …its like your mind is like every time thinking so much you know and then you have to do things for yourself anyway and you have to be strong , maybe in future, if like your mum or your dad or whoever then like…my mum passed away – I'm not coping you know, but I know I have to stand up for myself – I have to be strong – especially for my son you know…

Many of the participants also reported that they pray to God to keep them alive until their children are grown up and able to look after themselves. C stated:

> …in my life I am coping with my children first…because I already…my husband is dying…he passed away…in 2001…4 December…so now I am scared to die…because my children is too small…that's why I pray every day…I ask God to keep me until the children is getting big, maybe getting married…and then when he's growed enough then I can die (laughs)…

R reported a similar feeling, in that her worry about the well-being of her child motivated her to care for herself better. It motivated her to seek help:

> …but you know, I thought for the sake of my child I need to do something about it…and so I went to a doctor…who sent me here because that doctor knows Dr C…so I came and saw C and ja…we have been coming here since 96…you know for me and my child to still be alive and be here today…you know that they told me first that my child would probably die by the time she was three years old, you know…blah, blah, blah…but then she went onto ARVs and now she is ten years old and me too…I am only on ARVs two years now and I'm still strong…so as long as I am strong my child will not die…

P reported realizing the impact of her health on her child's anxiety levels and that this motivated her to stay well and keep mentally positive for her child. She even reported that she thinks her child's reactions and the way they motivated her, saved her:

> You know it is hard when my child gets sick…it stressed me a lot, but when I was starting to get sick and my child was fit…I worried for my child…I just prayed…and I never lose hope…I wanted to live for my child and I want my child to live for me…I want to see her going to high school, graduating… You know, when I was sick, my child's class teacher phoned me and told me that my child was crying…she was saying her mother is sick and she is scared I am going to die…but when she is at home she never cries or tries to sleep by my side…she just acts normal…all the disturbance was at school…so, now when I see her coming home from school I try to be strong for my child so she doesn't have to worry… It is my

child…she is a sensitive child…I worry will she cry all the time…ja, I think that she has saved me a lot…

C explained how she tries to hide her own pain and suffering from her children in order to protect them from sadness and worry:

> I saw my children is wake up and is looking me… I don't want to show the children I am sick…so I just go to the toilet…I'm just close the door…on my own it is a hard thing…sometimes I don't want to cry in front of my children…I cry in the bed…because the 11 year girl she knows everything now…when I am sick she is sad…

C also expressed a worry about the fate of her children should something happen to her: "…nobody can take care of them like me…even if their aunty or their uncle can take care…not like me…". However, this comment also shows how the significance of her role as mother to her children helps to give meaning and purpose to her life. M echoed this concern with her statement: "I worry a lot about me dying - but both, me and her - she gives me strength…to be alive…you see…even when I die I know there's my sister but it's not the same thing with her… ". O also reported worrying about her child's health and her child's care should she die: "…if I die who will look after her…also I worry for her to get sick…I was worrying when she was getting the herpes…I thought that maybe my child is going to die…". K stated: "I know I have to stand up for myself – I have to be strong – especially for my son you know", which suggests that the fact that she has a son is motivation for her to remain strong and to cope.

Many of the participants reported having integrated the caretaker role so much into their identities that caring for others was a part of their work. N described how she tries to educate children about HIV and raise funds for further projects. She also described how she feels this helps her:

…I have been doing a government project…funded by the Department of Arts and Culture…I go into schools and teach about HIV/AIDS…we talk about sex because they can't be open to their parents but they can be open to me…I am waiting for money from Lotto now…I want to take the project nationally…I am interested in KZN and what is happening there…especially in the rural areas…ah, excuse me…but this bloody government of ours…they are corrupt…what are they thinking…they give money to sports and people are dying and they are not giving money to the doctors…you know, that is why people are running away…the people I used to be with…teachers and nurses…we lose them because of our government…ah…I have to force money from the government…when they have functions…I take kids to perform there at the function and then I tell them that these kids need money to buy food because their mothers are not working and because their mothers are too scared to say that they are positive…

Interviewer: It sounds like you are a mother to everyone…

Ja…Mother Theresa (laughs)…

Interviewer: Do you think it helps you to help other people?

I feel happy if I help other people…

S also described how her job as a nurse in an ARV roll-out clinic is important to her:

I think also helping the other women in the clinic helps me…I think at least I am doing something good for somebody else…also it makes me feel strong, especially because I understand what they

are going through…I am thinking let me help this woman to be strong…it empowered me (laughs) to help other people…

R spoke about her calling to become a sangoma helped her to help others:

> Ah…it was ok…it was good…it is something from your family that is like a duty or something…like a gift…it is nice to help other people…I just see some people when they ask…I don't make money from it…I think I am just good at listening to people's problems and helping them think of answers to the problems….

O also spoke about how she tries to help other HIV positive women waiting in the queues at the clinic by telling them her story: "…when we are at the clinics we talk…like me…I was having all my nails out…and at the clinic I am telling people I was not having all these nails and look now they are all back…(laughs)…and they all say…oh…". R also described how she feels she needs to try to talk to and help other HIV positive people: "It is hard when I am walking tall and the next person next to me is very sick and they don't want to talk about it…I try to find a way to reach them…I tell myself that I must try…but if I can't it makes me very sad…". R went on to explain the reason that she feels she is called to help others: "…I think it was because they were too quiet…and I was not…even now…they are quiet and I am the one that is fighting…even in the hospital…the other people are just keeping quiet and I am the one saying hey, this is not right, you understand?".

T explained how helping others helps her to feel better about herself and her life: "…I am feeling proud to help them…ja, at the first when I was finding out I was feeling ashamed for the HIV…what the people would think…but now I talk a lot…".

Another area in which many of the participants reported playing the role of carer was when caring for sick family members. While caring for others allows these women to get in touch with a very strong survivor in themselves, it also seems to confront them with

their own vulnerability when they think about themselves in a sick role with others caring for them.

M described the period when her fiancé was ill before he passed away:

> Do you know when I took my fiancée home when he was ill…suddenly he collapsed and I took him to the hospital. I wasn't working by that time I was at home because I wasn't working - now I had to find job - he wasn't ready to go back to work because he had meningitis…so it was very difficult, I had to wake up in the morning half past four and do you know at night you won't sleep when some one is sick and making noise – it comes …he was always hot - then I had get up half past four to go to work …there was a cousin who was staying with him when I was at work…come from work…get inside the house…he's sleeping… 'did he wake up…eat little'…you know, those things…

In discussing the role of carer for a sick person, M went on to express her worries around the possibility of her child becoming ill, especially if she (M) is not around to take care of her and her thoughts on who would take care of her if she became ill:

> Because, to take care of someone who is sick, it's very hard - you have to wake up at night when she is hot or something, and she needs something…it takes a lot…I know they can do it but, takes a lot, you know…

> Interviewer: Who do you think would look after you if you did get sick?

> If my grandmother is still alive, she will, even my sisters – we took care of our parents…the one staying with me…she took care of my

dad …you know…my dad, when he was sick, he was very cheeky but she stood by him…I wasn't there…I wasn't at home. I was here and dad was sick…she did everything for my dad…everything…so she knows…

The vast majority of the participants also reported caring for and supporting parents, siblings and extended family.   N described her self as being: "…the baby, the breadwinner, the mother and the father…" for her family. She described how she has looked after her father and her siblings, despite having a stepmother with whom she doesn't get along:

> …I built two houses in the rural area for my family…the first 1988…I built a house but I was in America and I was sending money home…they were living in a mud house and anything can destroy that…so I was telling my father that he must just build a nice house for all of them and to leave one room for me when I come to visit for a holiday…only to find that when I phoned my sister she told me that my stepmother built only 5 rooms and that is not enough for all of them…and she is staying with other kids that she had before she married my father…so I decided to build another house in the same yard...so I told my sister she must be responsible for this house…you know

In addition to financially supporting her family, N also described how she tries to give advice to her family and protect them from HIV:

> …you know I am the bread winner and I am burying all these people…I would want the doctor to tell me in front of all the family, so even if the person is dead the rest of the family can protect themselves…I was telling my sisters that they must be careful because all these people are dying of AIDS…you know in

the rural areas they don't believe in things like condoms and stuff…I was telling them that they will die like peanuts if they don't take care of themselves…there is no witchcraft…it is all in your heads…you will die if you don't take care of yourselves…

While this role seems to provide many of the participants with purpose and importance in their families and is a source of pride for many of them, in some cases, being the 'strong one' in the family seems to make it more difficult for some of these women to take up a position of vulnerability, especially when it comes to disclosing an HIV positive status to their families. N describes how she feels she cannot yet tell her nephews and nieces, whom she supports after the death of their mother, her HIV positive status:

> …I'll tell them…it is just that they are relying on me…they will lose hope because they don't understand…ah, she is going to die and she will leave us…our mother died, our grandfather is married to a… and now if she dies we will be orphans…I don't want to tell them because I know they are weak…not like me…

P described a similar dilemma with regards to her mother. She explained that she has told her sisters and her sister-in-law her positive status, but has decided not to tell her mother:

> …a problem for me especially was my mother…she cries a lot, so I didn't want to worry her because with my brother and my sister-in-law she cried…you know older people…they just think of death…thinking I am the one who is going to bury my child and my child is not going to bury me…I'm looking for my child to bury me, you see, stuff like that…she cries a lot…you know…my brother's death…she didn't cope with it at all…she was even going to the doctor…getting sick all the time…stressed, I don't know…until she recovers…she is ok now…she is ok…but you can

still see sometimes when she sees my brother's picture…but she is ok now…to tell her now?...uh…I don't want her to go back to that stress. She will always be thinking about death…oh, my baby's going to die…she's going to lose another baby…its like you know these old people, it's like they don't know about HIV…there should be education for adults…for gogos to learn more about HIV and AIDS because when you tell the gogo I have HIV she is going to think you are going to die…

S also explained how she has financially supported her parents and her brothers:

> …you know…I had a graduation party and I invited church people to come and my family and my dad, he was praising me…he was saying…everything in this home…I built a house for them…he was saying everything you see in this house it is because of her…you see this house, my daughter she built this house for me…it was the first time I was hearing that he recognizes the good things that I do…I am the second born, but my elder sister who is the first born, she is working as a shop assistant…she is not a professional somebody…so I have to help my brothers with money to train for jobs…

However, she then also explained how she has told her sisters, but stated that she is afraid to tell her parents and her brothers:

> …I do have brothers but I didn't tell them…I don't want to hurt them…same like I didn't tell my parents, I don't want to hurt them (laughs)…at least my sisters…maybe it's women…women talk…they are understanding, they don't have a problem…in fact, I am scared to tell my brothers and my parents…you know…they are dependant on me…you know if you don't have information

about this HIV you think that somebody is going to die maybe early and I don't want to traumatize them… (laughs)…my father he loves me a lot…also he is dependant on me…I think if I tell them they will be very hurt…I don't want to hurt them…

T described a similar situation, in that because she is financially supporting her family in Zimbabwe, she is afraid to tell them her status for fear of hurting them or causing them to worry:

> …sometimes I used to worry…who is going to look after them if I am dead…I worry…I worry also about my family in Zimbabwe…they are struggling (starts to cry)…it is too hard there…I need to be strong to help them…we are sending food every month…for my mother and father…my other sisters they have their own husbands like me…the husbands are looking after them…because even my sister's kids…the one who is passing away…I am supporting her kids…to go to school…
>
> Interviewer: And your parents…have you told them that you are positive?
>
> Ah no…they don't know…I didn't tell them…I am scared…you see, my mother is someone who is having high BP…ja…because sometimes she is having a stroke and I am thinking that if I tell them that thing will come back again…there will be too much sadness…
>
> Interviewer: You're worried that will be too much for her?
>
> Yes…

Interviewer: Is it something you would like to be able to tell them?

…eish…no…I don't want to tell them…I am very scared…especially my mother…maybe she will end up dying…she is that person who gets too much shocked…even if I am sick I won't tell them…because I know her, even if I tell her 'mummy, I am sick' she will be too much worried…

Interviewer: Was your mother always like that?

Yes…because even that time when she have that stroke…it was when my younger sister was very sick, she have an accident…she hears that my sister is sick and she have the stroke same time…

O also reported fearing for her mother's health and for this reason feeling afraid to tell her mother her status:

Ah, my family…I am scared to tell them…you see my mother she is having high blood pressure, even if you tell her someone is sick, ooh she gets frightened, so I am not sure when I am telling her if she will understand it or what…she will shake and say…oh, my child…ja, if I tell her I am HIV positive, she will cry, ooh…what will she say…and I am having 2 sisters…I am scared…there is this younger sister and I wanted to tell her one day…but then I changed my mind…I am thinking, no, I am too scared…ah, they love me too much…so maybe when I tell them about this…I am the big sister…so maybe when I tell them they will worry… they love me too much…the big sister…I was always laughing with them…not shouting at them…I support them…I tell them they must do this…they mustn't do this…

Interviewer: It sounds like you are protecting everyone in the family?

Ja…I am the strong one…

S also reported feeling that her own mother's ill-health makes it difficult for her to disclose her positive status to her mother: "Ja, she is short-tempered person…but she is also sick…she has heart problems and arthritis and those sort of things…I am afraid…I think it will be hard for her if I tell her my status…I think just leave her…so she can look after her own sickness…". E also commented on how she takes a carer role towards her siblings:

> …even now…I'm still looking for them…the one who comes after me…he is working at KFC…he is the one who has never been lucky, he didn't get anything from me…but the other 3 they get a lot from me…I buy the 3rd one glasses, he didn't see well…then I took the younger sister to the college, she is now working at the Krugersdorp municipality in human resources…then the last one is still attending school but I am looking for her…

However, she expressed some anger at having been born into the role of the first born child and the responsibilities that this role entails:

> I used to get angry…oh no, why should I be a first born because I had to carry so many things…when things are happening they call me…sometimes I think no, why should we go…(laughs)
>
> Interviewer: So the family depends on you to come and sort things out?

Just imagine an older person calling you to come and discuss their matters …(laughs)

Interviewer: So it feels as if you are the mother actually…

Ja…the mother and everything…

E also commented on how she feels that at times the care that she offers her husband is not returned and how this hurts her: "He just care only to say some things sometimes…when you are sick he just leave you there…he can't ask if you need some porridge or what…you have to get up and make it…when he is sick… I look after him too much …".

M also commented on her role as the first born child after her parents died:

> Ja…do you know you have to especially when you don't have parents because when my dad passed away my brother was in form 3 and he was in boarding school…there wasn't money…I had to pay…he finished boarding school, he stayed at home a year, he went to work at …he didn't like it there…so I had to do a lot…I paid school fees for both of them…

She also explained how she tried to assist her sister to be more independent:

> …we were staying here with my sister here in town hah she was lazy…she couldn't do anything when she is home she is complaining…I told myself 'Ok now she is big, she has got a child, she can take care of herself, I have to move out so that she can take up'…so I moved out…ja, I fought…for her to be, you know, to do something for herself, to do something for her child…not always telling…go and do this, go and do this…and she

is stubborn…I go there to find out if she is eating well, because the first month, there were take-aways…then I told her you are going to be sick…lets go to the shops…we go, we went to the shops we bought pots, we bought plates laughs…she is lazy that one (laughing)…

Interviewer: It sounds like you were even still now a mom to her - that's the kind of thing a mom does…check how the person 's eating…buying plates…

That's what they want…if you don't phone or if you don't come to see them they complain a lot…they start to say hey, this and that, this and that…so I have to, everyday from Metrocard, phone all of them, my brother , my other sister…hey this one is tough - the one who stay here – this one, the other one – the one who is taking ARVs, she wants you to phone every day, maybe she depends on my support… 'you didn't phone to ask how I…' (laughs)…so everyday I have to…I am used to it – I am like a parent to them.   I have told myself that…

However, M also shared some unhappiness about her role as carer to her siblings and her extended family, explaining how she became angry when people expected help from her after she had needed help and no-one had helped her:

…and how to give, you know, in life…my dad used to give, give, give, but when he passed away on his last days…there wasn't anyone coming at home, to visit or help him, do you know?   He was a lonely man.   But when he had something he could give… people would come at home there was always people visiting, staying with us…and that was what was happening with me…I used to help a lot, but when I was struggling…you see no-one

helped a lot…but it hardened my heart…now even if I've got something…the other day my uncle asked me for money…I say 'I don't have it' and I had it …do you know it's not nice…if you are helping your family, you expect at some other time when you are in trouble, someone will come and help you, then that person doesn't…but I told him straight…I don't have money…

Thus, it can be seen that although these women take pride in being able to support their families, their role as carer or breadwinner or 'the strong one' seems to make it more difficult for them to access support from their families. They fear that by telling their families their status, they will hurt and worry them, and in some cases, fear that by telling their mothers their status, might even cause her death. However, in some cases the women described that having HIV and caring for HIV positive children caused them to rethink their roles. In E's case, she felt angry at having to be there for others when struggling themselves. In M's case, it caused her to re-think her responsibilities and to re-evaluate the boundaries of her relationships with others. Ultimately though, in the majority of the cases, it caused the women to try to find a new balance between supporting others and gaining sufficient support from others for themselves.

6.2.4.6. *Coping is being independent and self-sufficient*

For all of the participants the experience of coping with HIV has been a lonely and difficult journey. Coping was linked to the idea of being independent, self-sufficient and able to care for oneself. This theme repeated throughout the interviews. S stated:

…I think if you are independent…you can survive on your own without…without being dependent to somebody else…I think the way I grew up molded me up to this stage…because even now I am surviving alone…I am having three kids. I am taking care of them without any help…and my brothers and my mum and

dad…but I am not forced to support them because I am married but when I am having money I send to them…not every month…

C spoke about the pain she experienced while her husband was dying and how it contributed to her decision to remain single and manage on her own:

> …the stress…you know I was not understanding…nothing. The people was saying maybe he will die anytime but I was…I was thinking my husband will get better…you know I was wasting maybe R500 to buy that medication but it was not helping…but then he was dying and I just prayed to God to help me and keep me until I am dying also…and that is why I am not wanting another husband…not to marry anymore…until God will take me…it is hard and you know, I don't want a husband now anymore…I'm fine like this…

M spoke about having been independent from a young age, more so than her sisters who were younger than her, and how she feels this independence has helped her to cope:

> …it did help me, especially the one year when my dad and my fiancé passed away. It did help me a lot. It did. You know. I could take care everything . Ja. I could still…for everything. My other sisters can't…even the one who is here…even now my sisters are too lazy…do you know they are so lazy they can't even do anything… my back is sore, my feet are sore…because of my mum…I can do anything (laughs)…

K also spoke about how the death of her mother who had been very supportive to her contributed to her realization that she needed to stand up for herself for the sake of her son:

…it's like your mind is like every time thinking so much you know and then you have to do things for yourself anyway and you have to be strong , maybe in future, if like your mum or your dad or whoever then like…my mum passed away – I'm not coping you know, but I know I have to stand up for myself – I have to be strong – especially for my son you know, ja so, ja there are a lot of things you know…

P spoke about how her break-up with the father of her child helped her to find her independence:

Ah, you know I am not the kind of person who is open quickly with my problems…I try first to fix them…but if it goes on and on…then I tell them…like my child's father stopped paying school fees…I tried to phone him and phone him…and only when I couldn't get hold of him then I told my family…then my sister just payed the school fees…she helped me a lot…I kept trying to phone him…but only after a year he paid…and now, this year it's the same problem…I waited…you know, until he had another child…it took me a long time to realize that he doesn't love me anymore…it was hard that he left when I told him our baby was HIV positive…I am much stronger…I thought I was not strong but I am…like I have learned to do things for myself…like I used to always send news of my child to her father, but he never responded, so I learned not to bother him anymore…I didn't want to be like other mothers who when they split up they keep the child from the father…I used to take her to see him with my own money so she can know her father…but now, he doesn't show any interest…so I have stopped stressing about him…

Hence, it seems as if the losses that many of these women have experienced and the circumstances of their childhoods instilled a sense of self-sufficiency and independence, that many of them consider to be vital in their process of coping with HIV.

6.2.4.7. *Coping is not feeling sorry for yourself or having anyone else feel sorry for you*

For many of the participants, an aspect of their process of coping is being able to feel healthy, strong and capable. For many of them, a part of their fear of disclosing their status to others is having others pity them or say 'oh, shame'. This is something that many of the participants try to avoid for various reasons. O explained her fear in this regard:

> (laughs)…and not goes 'shame, shame'…maybe like other people would…
>
> Interviewer: What would it mean if people said shame?
>
> Ah, it would mean then I am very sick…and people can see…

P explained her fear of pity in relation to her mother:

> …but it is also because I don't want pity…and if she knows it will be that every time I come in the house she [her mother]…you know, maybe she will not want me to touch heavy things or to be working hard…and I don't want pity…because every time she is pitying I will be oh, I am HIV positive, oh I am HIV positive…and I don't want to think about it all the time…I just want to live my life…ah…I don't like shame…people saying shame…aai…I've got a lot of tears…it means that maybe this person sees that I am

sick and I don't see that I'm sick…I think I am like a normal person and then when I come in…they are like P, aai, shame…I don't like that…

P's comment highlights the fact that pity from others would cause her to be reminded continuously about her positive status and that this would not help her to cope. She feels that being treated as a normal person helps her to carry on living her life. She explained this in relation to the support she feels she receives from her sisters: "…I think it helps me a lot because I am not always thinking about it…they take my mind off it and they take me as a usual person…they don't see any change…and they don't feel pity…".

S also explained the reason she doesn't want pity from others and why she hides her status from those she feels will pity her. She explains why she chose not to go to church for a period after the death of her husband:

> …for a while I didn't go…while I was wearing the mourning clothes…when I take them off I became a church goer again…
>
> Interviewer: Why didn't you go when you wearing the mourning clothes?
>
> I was afraid they were going say shame, ah shame…you are still young…I didn't want them to say ooh, shame…
>
> Interviewer: How come?
>
> It traumatizes me…it makes me feel powerless…I don't want people to feel pity…it makes me feel helpless…it traumatizes me…

E's explanation of why she doesn't want to get sick and then have other people pity her also highlighted the sense of helplessness other people's pity would evoke in her:

> No (laughs)…making myself a baby…no, no, no…mostly I don't want to get more sick because people say 'oh, shame'…you rely on a person every time when you are sick… you don't get up yourself to get water…you will be looking for someone to bring it for you… I don't want to rely on people all the time for things like bring me water, help me to the kitchen…that is the thing that is making me to stand up…I don't want someone to work for me…I want to work for myself…I learned so that I have to stand up and that I must work hard…it is not easy for me to just sit down…

The participants all expressed the desire to be seen as strong and not as a person to be pitied. Their fears around being pitied included being reminded of their status, becoming afraid that they are sick enough that people can see their status and the fact that being pitied would cause them to feel helpless and abnormal.

6.2.5. Coping is finding meaning in their status and being able to invest emotionally in a future

Many of the participants described finding meaning in their struggle with HIV in their relationship with God. P believes that her illness and recovery were planned by God and that he protected her through her struggle. She described an incident that occurred when she was very ill:

> …(laughs) ah, God has been good to me…you know, when they sent me from here to Helen Joseph because I was so sick, I went to the mortuary by accident…then the sister says to me where are you

going and I said 'to the wards'…she says no, this is the mortuary…I thought hey, I really am going to die…but I got better…I am back to my weight…God is great…I prayed that he would let me be here for my child and he did…maybe he wants me to work for him more…he was testing my trust in him…

C also describes having had her relationship with God tested through her struggle with HIV and the loss of her husband: "At that time…I was thinking, not praying just crying, crying, crying…but now I am strong with God, I am praying…".

Like P, N also believes that her contracting HIV was a calling from God. She believes God allowed it to happen in order for her to learn and become more religious: "…so we go to church... for that…but today I know there is this thing that kills and no-one can cure it but God…that is why I changed my life altogether…maybe it was a calling from God…I don't know…".

S describes her journey with HIV as having led her closer to God because she feels that God has helped her to cope by creating situations where she was able to learn how to survive and gain support:

> Ja…(sighs) it was too much…I felt I wasn't coping…and I thought that I was placed in the clinic because God has a plan for me…I am newly diagnosed and now I am placed in such a clinic…I said at least I am going to cope because now I am going to get experience how to handle such issues…ja, I said God has a plan for me to be here…I think if I was placed in the wards and not at the clinic, I was not going to start ARVS and not going to send my child to the HIV clinic…because it took me time to send my child there…when I was first there I kept quiet for maybe two months and then I told my supervisor what is happening with me and my child and then eventually…I think the following month my child

started ARVS in my clinic there and that same month my supervisor escorted me to Helen Joseph and I started ARVS there…it was a blessing for me to be placed there because if I was not placed there I was having that fear…actually I think I would be dead now if I wasn't placed there…

For some of the other participants, the meaning they found in their HIV was through their relationships with their children. O explained: "It is a big worry…me dying or my family dying…but I think it makes the time together more special because we don't know what might happen…". K also described her relationship with her son being extremely close due to the HIV:

> …the thing is I'm so close to that boy – I'm so close even like if I went to I can say Pretoria to go and run – I just took him along...I know he can take care of himself - but not being around him is like… even like when I am shouting at him like we doing something wrong…but after two minutes I just go back to him – are you ok - you know it's like – I don't know…maybe because he is only my child I don't know…I don't want to put like a guilt to me that maybe I just put him in this situation you know…I just put him in…I didn't know…but sometimes I feel guilty like you know but anyway I have to let it go and move on with our lives as he moves on with his life and then ja but for him it's not easy…it's not easy…but he plays, he plays very well with other kids- even though like we didn't like…ja…tell them like he's positive - its only my sister and even his friends doesn't know, you know…

R also spoke about feeling that her relationship with her daughter is really strong. She commented that her child's survival is what gives her existence meaning:

> …you know for me and my child to still be alive and be here

today…you know that they told me first that my child would probably die by the time she was three years old, you know…blah, blah, blah…but then she went onto ARVs and now she is ten years old and me too…I am only on ARVs two years now and I'm still strong…so as long as I am strong my child will not die…

Finding meaning in their situations and focusing on the positive changes in their lives has helped many of the women cope with their positive status.

Focusing on the positive is something that many of the women said they did in order to cope. When explored in more detail, it turned out that some of the implications of focusing on the positive were that these women found hope and began to feel that they had a future that contained positive things. Many of them felt that these things helped them to cope. P's advice to other HIV positive women emphasized the importance of having hope: "…I think that for the people who are sick, they must eat healthy and not spread the disease…and they must not lose hope…there was no cure for TB and now there is…so maybe one day there will be a cure…".

Many of the participants also felt that they managed to stay hopeful through their relationship with God. N explained: "Ja…that is why when I find out I am HIV…I was thinking this is a minor thing…and I still have hope…maybe they will find a cure…I gave myself to God and now I am free…". C also explained how her relationship with God and with her church helped her remain hopeful and strong:

> …I give it all to God and now sometimes I am happy…sometimes you got the worry…but sometimes not…God he help me…in the first I was not strong…I was crying all the time and I was asking God why he make my husband sick…in my life…the church first gives me hope…I am strong in the church …I am praying and sometimes I am fasting …you know one day I am not eating and

then maybe half past 7 then I am eating but in the day I am praying
to God…

Many of the participants also emphasized the importance of accepting the changes that HIV made to their lives and embracing the life they have. C stated: "…but now I got a new life after my husband he die…I have to budget the money to get everything for my children…". P also explained the importance of realizing that her life was not over and that she could still do much of what she had planned for her life:

> …and it was then that I started to understand and every time that I
> was here…there was a sister…she was very supportive…told me
> to come for appointments…she also helped me to think, okay no it
> not the end of the world…what I want to do whatever I want to do
> I can do it…

P also explained how she managed to remain focused on the future and living her life through her hopes for her child:

> You know it is hard when my child gets sick…it stressed me a lot,
> but when I was starting to get sick and my child was fit…I worried
> for my child…I just prayed…and I never lose hope…I wanted to
> live for my child and I want my child to live for me…I want to see
> her going to high school, graduating…

For many of the participants, the support they received from family, friends and the church helped to maintain their hopes for the future. A belief in God and faith was also cited as giving hope. For others, their children's futures helped them to remain invested in their own futures.

6.3. INTEGRATION OF THEMES: COPING AS A PROCESS OF DISCONNECTION
        AND RECONNECTION

Upon initial analysis it became evident that these women view coping as a process. S stated: "…experience teaches you a lot…and it takes time to get to a place of coping…I've been through a lot…I've been struggling, but now it feels like my things are coming alright…". This comment highlights the nature of coping as a process in that S believes coping comes after a period of struggle and that it takes time to reach a stage where you feel you are coping.

It also became clear that they do not feel that coping is a static state of being or a certainty once achieved. As O remarked: "Ja…I feel I am coping…but sometimes when I think too much (laughs) I think that maybe I am not coping…". This comment also suggests that coping is subjective i.e. that coping is changing and dependent on mood and circumstance. This sense of coping being a shifting experience is echoed in M's opinion: "Ja…for now I am coping…I have started coping. I haven't been coping, but now I have started coping – I see my life's got some direction…I try, but you can't balance these things…(laughs) you can't…".

P defined coping with HIV as: "Aah..it is like I have accepted that I am HIV positive…I am dealing with it…and as long as I am not getting sick or stressed by it…I am living a life just like any other normal people…". This statement highlights two important ideas. Firstly, it supports the idea that coping is a continuous process. In the context of coping with an HIV positive status P suggests that coping entails continuously "dealing with it". Secondly, it highlights the idea that coping is linked to acceptance. Accepting one's status implies reaching a place of less inner conflict around HIV.

According to the participants' comments, the process of acceptance seems to mirror the process of coping. S stated: "…I just accept…I cannot change the situation…I must just deal with it…". And K stated:

> To be positive with life – especially ………, my friend he didn't
> want to accept, he didn't want to accept and as I read the articles
> most to read or whatever I just hear that the main important thing
> is to accept – acceptance.   And then deal with it – HIV is not a
> killer disease, especially it's like it's only you who is going to kill
> yourself while you don't accept…

From the participants' statements around coping, a pattern in their descriptions emerged as to their experiences. This pattern or process consists of a series of disconnections and reconnections and begins when they first discover their HIV positive status. It was interesting to note that in all the interviews, when asked around their experiences of coping, the interviewees spoke about their experience of coping in the context of relationships. In each case, these relationships included the woman's relationship with her family – her parents, her siblings, her children, her partner(s); her relationships with friends; her relationships with bosses and co-workers; her relationships with other HIV positive women in the clinics; her relationships with doctors, nurses, counselors and psychologists at the hospitals and clinics; her relationships with neighbours and the community as a whole; her relationships with the church community, ancestors and God; her relationship with herself; and her relationship with the HIV in her body.

In each story that was told about the process of discovering herself to be HIV positive and the process of not coping and then eventually coping after this, each women spoke about the impact that the HIV positive diagnosis had on her identity and the changes it brought about in her relationships. They described a great deal of internal conflict or distress and feelings of ambivalence.

The theme that seemed to repeat throughout the analysis was a re-negotiation of closeness or distance in all their relationships – an urge to disconnect in order to protect themselves from loss and an urge to re-connect in order to feel comfort, love, acceptance, belonging, a sense of being 'a part of', and a sense of being alive.

The Human Immunovirus is a virus that seems to embody this conflict. HIV is, in essence, a disease of connection. It is contracted through connection with an other, through the connection of bodily fluids. Once in the body, it does not remain a foreign 'other', but rather connects itself to the body's DNA, becoming inextricably linked.

When the women talk about HIV changing their identity, this can be understood even on a genetic level. The Human Immunovirus links with DNA in the body, irreversibly changing and mutating. After contracting HIV, even their genetic material is changed. On a cellular level, who they are has changed.

On the other hand, HIV causes a disconnect between bodily systems. HIV disables the body's immune system and prevents the body from being able to defend itself effectively against opportunistic infections. Ultimately, HIV can cause a disconnect between the body and its ability to live – with death being a disconnect from life.

These changes that occur on a cellular level seem to be mirrored in the experience that these women describe in terms of their relationships, starting with the relationship with themselves. The initial discovery of her HIV-positive status was described by all the women as being extremely painful and as a time of not coping.

When discussing the time she first discovered her positive status, M stated: "It was horrible. I was angry and I didn't know what to do…I didn't even tell my fiancé." R related her experience of the first few weeks after she found out her status: "I don't know…how I coped…I don't know, really…because sometimes when I was alone I would just cry a lot…a lot…". T explained:

> Ja…for the first time I was very, very shocked…I was thinking
> that I am dying…I was crying…I was even scared to tell my
> husband…ah it was very hard…I think the time that I find out I
> was thinking maybe I can die today or even tomorrow…I was not
> thinking I can live longer…because I was thinking maybe to give

up on life, you see…I was thinking maybe it was going to be the end of me…

These comments suggest that the time when these women first discovered their status was an extremely emotionally painful experience, filled with shock, anger, sadness and despair. There is a sense of helplessness and confusion, of not knowing what to feel, think, or do. This stage is the first disconnect that is observed.

Many describe a feeling of being disconnected from themselves and from life. M stated: "…that was a hard year of my life…it was like drifting…it wasn't me walking". M described feeling completely disconnected from herself. Her statement that it 'wasn't me walking' suggests a sense of being someone else.

The next disconnect that is observed is away from others. Many of the women describe a time where they isolated themselves, withdrawing from their relationships. Both R and K speak about spending a great deal of time in their bedrooms, crying alone, and not sharing their worries with anyone else. Many of the women described needing time alone to think, mourn and process the news before being able to tell anyone else. The time before telling another person differed between the women as did the choice of person to tell first. Some chose to disclose to more than one person, however, the time taken to make these decisions differed. For some of their relationships this time was hours, for others weeks, for others years, and for some relationships, the time is forever. Many of the women made the decision to not tell their parents their status ever, deciding that their parents would feel too sad and too worried and that their parents might not be able to cope with or survive the news.

The idea that there is a withdrawal from life itself is clear in T's statement: "…I think the time that I find out I was thinking maybe I can die today or even tomorrow…I was not thinking I can live longer…because I was thinking maybe to give up on life, you see…I was thinking maybe it was going to be the end of me…". Being confronted with the knowledge that they have contracted an illness that can kill causes them to confront their

own mortality and the eventuality of their deaths. For a time this seems to disconnect them from life and even the wish to live, as can be seen in T's words: 'I was thinking maybe to give up on life'.

While the disconnects from themselves and life seem more related to the women's attempts to cope with overwhelming emotion, the disconnects from others seem to allow the women space to cope with the changes occurring within themselves. The separation from others also allows them to think about the changes that may be necessary in their relationships.

There is a strong sense of isolation, in that many of the women chose not to tell their partners straight away, as if needing time to process their diagnosis and its implications first. This idea is supported by S's statement: "Ah…initially it [her HIV positive diagnosis] was a secret (laughs)…I can say, initially…I don't know whether I can say I was in denial, but I didn't accept it initially…it was not easy to talk about it…I think I have accepted it, I can talk about it now…".

The idea of initial 'paralysis' and needing time to process the diagnosis and feelings first, before moving into any form of action, is highlighted by O's description of her husband's process after she informed him of her positive status and their child's positive status: "He is saying to me…just that he is not prepared to go [to the clinic]…later he is saying that ok, now he is prepared to go…".

Once the initial shock and disbelief has passed, many of the women describe a time of ruminating over the diagnosis, a time when they "think too much". This seems to be the first reconnection that occurs as the women connect with themselves and begin to process the pain feelings. This time is filled with emotions like regret and guilt towards children and partners and anger towards partners and God for letting this happen to them. S reported: "Ja…it was very hard…I felt guilty…I was thinking maybe if I had tested during pregnancy maybe I could have saved my child…". T reported: "…he [her husband] doesn't have a mother…he is looking after his father and his small brothers…so

I was feeling really shame for him…that is why it was hard to tell him…I was scared to hurt him…that maybe he would be so stressed that his CD4 would go down…". O reported: "I was just asking myself how can God punish me like this…". N reported: Ay, I was angry…I wanted even to dump him [her partner] …it was even before the marriage…I wanted to stop with the marriage…I told him not to…we must stop and he must just forget about me…I told him I'm going to take my kids away from him…". K reported:

> Really - I don't know, I don't know – especially when I see the way my son was, because he was very sick, very weak.   I just blamed myself I just…ah…because his father couldn't … not knowing what was the reason so I just…after that month with HIV then I just… everything just came – I just asked myself – maybe he knew…or maybe didn't knew, I don't know, because that was 1991 so I don't know if he knew – but anyway, ja…I couldn't tell anyone, couldn't do anything – I couldn't – I just asked myself why but anyway…

P reported a similar experience:

> …at first I was not sleeping at night…it felt very unfair…like why me…because at that time it was we knew that if you slept around you get AIDS and I didn't do that…I got it from my boyfriend. Maybe if I had slept around it would have been better…I was asking God…

These feelings seem to begin a process whereby these women re-negotiate their relationships and the roles that they play in them. Many of the women described this time of re-engaging as entailing a renegotiation of their relationships. E describes the process of dealing with her anger and re-negotiating the relationship with her husband:

> Ah…when I am sad I don't speak…my husband knows that I don't speak to anyone…and sometimes I get the anger…I used to get this anger but the past 2 years it has gone away…I used to get angry and take some glasses (laughs)…he would hide…it took some days…but he didn't say I better leave her because of this anger…he stayed…he is a patient man…but I am better these days we can talk…he doesn't like me to be angry or sad, he want me to speak…

This process of renegotiation of relationships seems to include these women's relationships with God. For many of them, feelings of anger and fear of punishment give way to a sense of still being loved and protected and a reconnection occurs. C comments:

> When my husband is passed away I said that God did not listening me…because why he take my husband…he is supposed to take me before he take my husband…that time I didn't believe…really, really in God…but now I just keep strong because now I am alone and this is why I am believing God…trust God everything…

Eventually, this time of isolation, hopelessness and anger slowly gives way to a time when the women describe starting to cope. This seems to be when they begin to reconnect with others again. T described this time:

> Because I used to come here to the hospital for my appointments and I meet some other ladies, same like me…that is how I started to cope…it helped me a lot…because at home there…most of the times I was feeling lonely and thinking that I am dying…but then at the time that I started to come here and join the other ladies I see that there are many other people outside with this sickness…it's helping because most of them if they are coming to that place they

are shocked, but after that I am seeing them starting to be happy and talk with others because others when they are first disclosed they are crying too much but then they are talking with the others…they see that they are coping and it helps them…

T's description highlights the importance of support from others and is echoed in P's report of this time for her:

> Ja…but in fact I was not accepting it because when I found out my child was HIV positive she was 4 years old…it was hard for me to believe that she was HIV positive…I even took her to other doctors, but I didn't want the other doctors to take blood…because…I was told here at Coronation that my child was HIV positive…they took blood from her and then they told me that she is HIV positive and then after that I did not want to admit that I am HIV positive and my child is HIV positive…I didn't want to think about that…but my child continues getting sick…and I didn't want to bring her here at Coronation…because of here she's got the record here at the hospital…I was scared…scared…what if I take her to Coronation hospital…they are going to find the file and ask me…why I kept the child…so I continued taking to other doctors but not telling the doctors what is the status of the child and then…I don't know…when she was six years old...it was when she become very sick and then I had no choice…I had to come here…then they gave me the psychologist to explain to me that she is HIV positive…it is not AIDS, she is not going to die…and it was then that I started to understand and every time that I was here…there was a sister…she was very supportive…told me to come for appointments…she also helped me to think, okay no it not the end of the world…what I want to do whatever I want to do I can do it…

For many of the women this time of reconnecting with others and sharing their pain is difficult. K's comment highlights feelings of ambivalence around whether to trust others with her problems:

> …sometimes I close the door of my bedroom thinking, stressing myself , or depressing myself you know, ja because I think no one's going to help me you know – that a problem that I have because most of the people they see I have that attitude of not telling because they end up like sitting around all day seeing me by ……like this – something, something's not right

O's description of this time highlights the relationship between acceptance and coping as she explains how she came to accept her positive status:

> …what can I say…you know, at first when I found out I wasn't laughing…I thinking too much, but then I was accepting it…I can't change it…I am HIV positive…I accept it and I keep on…if I cry or be sad, nothing is going to change…I have to accept it…it was hard at first…I told myself…I have to just accept it…I am HIV positive, nothing's going to change and I must go on with my life….even if I get angry, nothing's going to change…even if I don't want to hear about it …they will talk about it [on TV], let me just hear about it…I've got it…I have accepted that...knowing where it come from is not going to help me…there is nothing that is going to change that…maybe it can hurt me more…(laughs)

These comments suggest that coping is a process of initial emotional turmoil, disbelief and not being able to accept the diagnosis that gradually shifts into an acknowledgement and acceptance of the diagnosis and its implications for their lives. This is accompanied by a willingness to start to engage with their lives again and the changes the HIV positive

status has made to their lives. This can be regarded as the stage of reconnection with life. When asked if she felt she reached a place where she was coping with her status, K's reply was: "Ja, definitely I do – I do…because I just accepted my status and then ja, just move on with my life…", which highlights the link between coping and getting on with the task of living.

Many of the women also speak about reaching a place where they feel the HIV diagnosis improved their lives, as it caused them to review their priorities and invest more energy into their relationships with themselves, their partners and with God. This attempt to find meaning in their experience can be regarded as the final reconnection with life and a future. P stated: "I am much stronger…I thought I was not strong but I am…like I have learned to do things for myself…". N stated:

> …but I accepted everything…even through prayer…after all these days I think God was just calling me…because I know this [HIV] is a demon thing…if you say I'm bowing down before it, it will kill you…so I just change everything and I took everything to God. I'm a Christian now, I'm praying…even my husband he is a Christian now…today I know there is this thing that kills and no-one can cure it but God…that is why I changed my life altogether…maybe it was a calling from God…I don't know…if I saw things that I've been doing as an artist…it was not good for me…even for my husband…you see, he couldn't affect me if he was straight…even if I was cheating or he was cheating…but we couldn't end up there…because of the devil things we were doing we ended up being positive…

N went on to describe how after discovering her HIV positive diagnosis and after a period of feeling very angry with him for not disclosing to her earlier, that their relationship improved and that she experienced him as being more supportive towards her: "…he is a musician like me, I am a musician…he used to go out and perform and

come around maybe 2 o'clock in the morning…but he changed and after performing he would come straight home…ah…he was supporting me…"

O described how she felt that her HIV positive diagnosis and that of her husband and child had allowed her to fully appreciate the relationships she has with them: "It is a big worry…me dying or my family dying…but I think it makes the time together more special because we don't know what might happen…". E described a sense of having been saved by the HIV diagnosis:

> Yes I think so…because for now I have to focus on the positive side, especially when it comes to my child…since I have discovered that I am positive I have changed my life…because at the first time I have been into alcohol…I was going out and since I have found out that I am positive I leave all those things…and I didn't want another child since I know that…that's the thing that I'm looking forward to…to do with my life…I don't see any friends because I am busy all the time…I am self-employed…it is like a tuck shop…my job…I am only going out when I have a reason…not just…and the thing that makes me not to go out is that I have collected myself and going out is going to lead me to wrong things…(laughs)…because all my friends…we used to go out whole night, like that…and they are not collected now…even when I see them on the street…when I visit my mother I see my friends…but they have never changed, they don't grow…what is happening with these people…

E's comment also suggests that working and having a job or a business helps with the process of re-engaging with life. This was supported by M's reflection on the difference between her and her sister when it came to starting to cope with an HIV positive diagnosis: "Oh it was – I was not coping - she was not coping…I thought of this a lot. But I could work - I could go to work, she didn't want to go to work – she wanted to lock herself in the room. I went to work even when I wasn't feeling ok - I went to work…"

From the above comments, it is clear that coping with being HIV positive is an ongoing process that starts with a time of not coping that gradually dissipates with the reinvestment of energy back into living. Many of the women describe a sense of coping, but not coping, and the acceptance of these two 'states of being' co-existing. They describe a process that is much like a continual movement along the continuum of coping and not coping, feeling at times closer to one end of the spectrum than at other times. As K stated:

> Jo! (laughs) no, we are coping, we are coping…especially as he [her child] grows up you know, but anyway we are coping, we are coping even though we are not coping, but anyway. You know every time you wake up in the morning, just see the sun – you just say thanks god, you know we are coping even though it's difficult, ja.

This comment on coping suggests that coping and not coping can exist at the same time, which suggests that while an HIV positive woman might be coping with one aspect of life, another area may feel more difficult and there may be a sense that she is not coping in this particular area. Thus it may be more useful to think of many continuums of coping rather than merely one, with each continuum representing different areas of these women's lives. These continuums seem to interweave, each affecting the others and, in turn, being affected.

Hence, it can be seen that, according to the participants of this study, coping is a continuous process that encompasses not coping at times. For them, coping entails a series of disconnections and reconnections as they move through a great deal of emotional pain, eventually reaching a stage where they, at times, feel they have accepted their status. It is about having grieved for and recovered from loss – of health, family members, partners, friends, financial security and babies that might have been. It is about having felt alone and isolated and then managing to reach out and disclose their status in

order to gain emotional and practical support for themselves and their children, and in order to help and encourage other HIV positive people. It is about being able to re-engage with life and relationships – be a partner, wife, sibling, child, employee as well as a mother to their children. It is about moving through a fear of stigma and discrimination and a sense of shame to finding an inner strength and pride in being a caretaker. It is about finding a reason for or meaning in their having contracted HIV or a sense of peace with not knowing and a trust in God's will or life's bigger plan for their lives. It is about being able to have hope and move forward into a future that they know holds more pain, loss and suffering, but that they can still believe also holds joy, love and meaning.

6.4. CONCLUSION

This section presented the results of the study and the participants' experience of coping was elaborated under six themes. The theme of coping with the impact of an HIV positive diagnosis on sense of self, roles and relationships was broken down into a further seven themes. The last theme: coping as a process of disconnection and reconnection was written as a meta-theme as it incorporates all the other themes. The following chapter will present a discussion of the results with relevant literature attached in order to provide an integrated understanding of these women's experiences of coping with HIV/AIDS.

CHAPTER SEVEN

DISCUSSION OF RESULTS

I stand

And suddenly understand

That you, Deep Night,

Surround me and play with me,

And I am stunned…

Your breath comes over me.

And from a vast, distant solemnity

Your smile enters me.

Rainer Maria Rilke – The Vast Night

7.1. INTRODUCTION

The previous chapter outlined the main themes that emerged from the participants' description of their experience of coping with HIV/AIDS. These included coping with a variety of kinds of loss, coping with changes in relationships, moving through fear of stigma, being able to talk about their status and accept support, being self-sufficient and being able to maintain a caretaker role and being able to find meaning in their status.

Anderson and Doyle (2004) conducted a study to ascertain the lived experience of HIV-positive African women living in the UK. Their study found that the majority of women reported a change in identity after receiving their HIV diagnosis. This included a sense of being a different person or of feeling dead and alive at the same time. This theme was also found in this study with many of the participants describing feelings of being disconnected from themselves and feelings of ambivalence about being alive and about dying.

Anderson and Doyle's (2004) study also found a theme of protection. Most of the women in their study reported feeling the need to protect themselves and their loved ones from physical and emotional harm. This was often achieved through the creation of more secluded lives and the avoidance of intimate relationships. The themes of disconnecting from others and taking on a care-taking role was also found in this study.

Lastly, Anderson and Doyle's (2004) study found that some women described how living with HIV and its associated problems had given them additional insight. Many described feeling 'closer to God', 'more courageous', 'more mature', and more grateful for what was 'precious'. Again, the current study also found these themes of re-connection in relationship in ways that seemed more meaningful.

Mayers, Naples and Nilsen (2005) conducted a study into feelings of loneliness experienced by HIV-positive mothers receiving public assistance in Canada and found that the mothers struggled with a variety of issues including "guilt, responsibility and

choice, helplessness and control, death anxiety, loneliness and isolation, and meaning and authenticity" (p. 93). Mayer et al. (2005) stated:

> With respect to psychological coping strategies, our findings indicated that despite the added burdens of poverty and a stigmatizing disease, these women were able to turn their health crisis into a growth-producing and meaning-giving experience. More specifically, their children came to serve as a crucial meaning-giving force in their lives, a force that motivated them to forge ahead and meet with courage the existential challenges they faced (p. 93).

While it is useful to find corroborating research conducted amongst different populations of women living in different circumstances, this study aims to deepen the understanding of these findings by linking them to existing theoretical conceptualizations of the themes found in the participants' experience.

This chapter presents a discussion of the findings from the previous chapter in light of relevant literature and theory in order to provide a theoretically integrated and culturally appropriate understanding of the participants' experience of coping and living positively with HIV/AIDS. The interplay between disconnection and reconnection seems to be the central thread that runs through these women's processes of coping and will be the focus of this theoretical discussion. While disconnection and reconnection can be viewed as a reaction to loss and inevitable aspects of the mourning process, they can also be viewed as a process of separation and a reunion or reintegration with the self and others. Hence, this theoretical discussion aims to show how, for these women, coping with an HIV-diagnosis entails further individuation and how this individuation can be seen as a process of mourning.

7.2. THRIVING IS SURVIVING THE HERO'S JOURNEY: HIV/AIDS AS A CATALYST TO FURTHER INDIVIDUATION

7.2.1. Introduction: The Hero's Journey

According to Allport (in Jordaan & Jordaan, 1985): "Man finds himself 'thrown' into an incomprehensible world…He lives in a whirlpool of instability, aloneness, suffering, and is haunted by the ultimate spectre of death and nothingness. He would like to escape from the burden of anxiety, but he would also like to know its meaning" (p. 769). The Hero's Journey (Campbell, 1972) is the quest for this meaning. Often in mythology the metaphor of the cripple is used to symbolically represent those in a state of psychological crisis. Often broken in spirit, they are unable to function in their usual ways. However, paradoxically, the suffering associated with being crippled, blind or otherwise disabled in mythology is also associated with the gaining of wisdom. This process "…in the language of the mystics…is called the dark night of the soul" (Sharp, 1998, p. 110) and these people are often regarded as heroes who have conquered some insurmountable suffering (Sharp, 1998). Wallace (in Lukoff, 1985) reports that the theme of the journey is often interpreted as a symbol for inner development.

Campbell (1972) studied the patterns of themes in mythology across time and stories within cultures and he identified three common stages within the 'Hero's Journey': Separation, Initiation and Return.

The experience of coping with an HIV positive diagnosis, and the implications of this, as described by the participants in this study can be likened to the stages in Campbell's (1972) Hero's Journey. The stage of Separation can be understood in terms of the time after being diagnosed as HIV-positive. It is a time of separation or disconnection, in which she begins to move from the world she knows to the unfamiliar or unknown; a time of Initiation or working through, which is where she enters the unknown and meets demons and dragons and must survive a series of tests; and then after having survived this ordeal she must now return to the world that she previously knew with new qualities

in order to set things right, which is a time of reconnection or return to participation in life (Lukoff, 1985).

In other words, the journey entails the overcoming of a physical and emotional struggle and the subsequent integration of the new information gained from it into their previous understandings of themselves, others and the world. It is important to note that the disconnection and reconnection or Separation and Return described in this study are not necessarily a physical experience but seem to be a predominantly psychological experience.

The 'Hero's Journey' (Campbell, 1972) can been likened to both Winnicott (1965) and Jung's (1933) concepts of individuation. Although Winnicott (1965) wrote about the very first individuation between mother and child, certain elements of his theory can be seen to relate to the experiences of these women. Both Jung and Winnicott's theories speak about vital separations which allow space for the development of a self. This chapter aims to show that individuation, which is a move from dependence to a place of greater independence and responsibility relates to these women's experience, in that their HIV-positive diagnosis causes separation and a re-evaluation of their sense of self, their relationships with others, including God, and their relationship to life itself.

While Winnicott's (1960b) theory focuses on the development of self in infancy, Jung's (1971) theory focuses on the search for the Self in adulthood, which incorporates all aspects of the personality and which is connected to God, others and all that is. According to Jung (1933) this search is usually reserved for the second half of life, however, an HIV positive diagnosis seems to disrupt the natural order of Jung's (1933) stages of adult development. Upon the discovery of their HIV-positive status, the participants of the study are called upon prematurely to face losses and their own mortality, which are normally associated with aging. "The patient is in the process of losing everything and everybody he loves" (Kubler-Ross, 1970, p. 77). The participants are propelled by their positive diagnosis into the stage of development reserved for the old. According to Sharp (1998) sometimes something deep inside demands that the

journey is lived out. Nature has ordained it and the cripple is offered the opportunity to become the hero. Writing on Jung's concept of individuation, Fordham (1953) states:

> But there are some who are forced to take full account of the unconscious, who must find a way to know it and accept its life side by side with that of consciousness, who must in fact integrate it in such a way that their personality is whole. For, paradoxically, the Self is not only the centre, but represents the whole man; making a unity out of the contradictions of his nature, all that is felt to be good, and all that is felt to be bad; maleness and femaleness, the four functions of thinking, feeling, sensation and intuition; the conscious and the unconscious" (p. 64.)…"Individuation is not usually the aim or an ideal for the very young, but rather for the mature person or for those who have been impelled by a serious illness, a neurosis, or some unusual experience to leave the ordinary safe paths and look for a new way of living (p. 78).

The crisis of being HIV-positive threatens these women's sense of safety internally and externally and demands that these women confront a variety of painful emotions and integrate these new experiences into their views of themselves, their relationships and their outlook on life in order to keep on living.

As discussed in the integration section of the previous chapter, coping seems to be a process which involves a series of disconnections and reconnections in the participants' lives. These disconnections and reconnections relate to the self and identity of these women, their relationships with others, their relationships with God, and their relationships to life itself.

The following discussion integrates Campbell's (1972) Hero's Journey with Jung's (1933) individuation process and Kubler-Ross' (1970) stages of grieving. Where relevant, theoretical constructs from various object relation's theorists and positive

psychology are also used. It is important to note that, much like Kubler-Ross' (1970) stages of grief, Jung's (1933) individuation process does not necessarily follow an exact set of steps and that each person's experience is unique. As mentioned previously, these theories are not usually integrated and may initially seem to be uneasy bed-fellows, however, they do all have in common the idea of moving from a state of distress or unintergration into a place of calm, acceptance or greater integration. Positive psychology describes a number of important and relevant concepts with regards to coping, however, does not manage to capture the process of coping, the 'how', or the journey entailed to get there. According to Goggin et al., (2001), in their study into HIV positive women's perceptions of the positive and negative aspects of living with HIV:

> Overall, it is striking that even in the face of a stigmatizing physical illness and moderate distress, the women in our sample were able to identify a variety of positive events that had taken place since their diagnosis. However, there were two women who were unable to identify anything positive. Why some women are able to adapt to being HIV positive and find positive meaning in the experience and others are not able is an important question, which should be the focus of future research" (p. 87).

Hence, an integration of theories is used to attempt to capture the full process that these women describe. From the meta-perspective required for such an integration, the process of coping can be seen to be a dynamic, conflicted, yet hopeful process.

7.2.2. Separation: Shock, isolation and denial

The experience of the Hero's Journey usually entails feelings of despair, loneliness and a desire to escape or hide (Sharp, 1998). The participants explain that the first discovery of their status was an extremely emotionally painful experience, filled with shock, anger, sadness and despair. There is a sense of helplessness and confusion and a description of

not knowing what to feel, think, or do. According to Kubler-Ross (1970) initial denial is evident in the first stages in almost all individuals who are informed that they have a terminal or incurable illness.

The data from this study revealed a suggestion of an initial 'paralysis' and of needing time to process the diagnosis and feelings first, before moving into any form of action. Denial can be viewed as an avoidant coping style and according to Folkman and Lazarus (1988) avoidance occurs when people try to avoid the problem and the associated emotion altogether. However, according to Kubler-Ross (1970) denial is useful and adaptive as it acts as a buffer after shock and it allows the individual time to mobilize other, less extreme defenses.

Denial as a defense mechanism is described as being one of the earliest, most primitive forms of psychological defense and is related to the primitive defense of splitting (Klein, 1946). Splitting is reported to be an innate tendency developed through evolution, where a person's ability to differentiate between good and bad quickly allows for the making of a survival promoting decision (Kaplan & Sadock, 1998). Bion (in Waddell, 2002) saw the primary conflict of life as being the predicament of experiencing both the desire to know and understand the truth about one's own experience, and experiencing fear and a resulting aversion to that knowing and understanding. Hence, the initial denial utilized by the participants seems to be a reaction to the aversion to 'knowing and understanding' due to the fact that the pain of fully 'knowing' their experience is too overwhelming at first.

In the lives of these women, their HIV-positive diagnosis represents an extremely painful, life-changing reality. Hence, their initial denial can be described as an unconscious avoidance of this pain and even as a temporary split from reality. While the HIV-positive diagnosis represents the first separation from life as it was before and heralds the beginning of the Hero's Journey, the denial that accompanies this separation at first, as well as being a defense, can be seen to contribute to the initial 'Separation', as it represents a disconnect from the participants' emotions and authentic experience. This

disconnect is then mirrored in the participants' experience of themselves, their relationships and their sense of being alive or belonging to the world of the living – and their investment in being alive.

Many of the participants described feeling disconnected from themselves. M's comment: "…it wasn't me walking…" demonstrates the extent to which this disconnect can occur. This sense of 'not being me' can be likened to Winnicott's (1965) description of the initial stages of infancy, where there is no ego and the anxiety that is experienced is felt to be a threat of annihilation. This is not a fear of death, but rather a fear of not existing at all. In other words, for many of these women, the self that they thought they were does not exist and they are suddenly unintegrated and extremely fearful.

Klein (1946) focused on these primitive anxieties and the development of defences against them, namely splitting, projection and introjection. Klein (1946) describes aggressive and destructive impulses that are more deeply rooted than the hate and anger associated with reactions to frustration that occur in later stages of development. Winnicott (1960b) also writes about the development of ego mechanisms of defence in psychodynamic theory and how, when overwhelmed, primitive defences are used, such as splitting, which results in various of the individual's instinctual tensions being experienced as not a part of the self (Winnicott, 1965). It could be said that these women have temporarily regressed into a paranoid-schizoid position (Klein, 1946). This notion will be discussed in more depth later in this discussion.

However, Winnicott (1965) also appeared to view the development of a personal defence system as an integral part of the journey to independence. Winnicott (1965) explains that the formation of these particular defences presupposes a separateness of self and the beginnings of a structuring of the ego. In the case of these women, this would be viewed as the beginnings of a re-structuring of the ego.

There is also a disconnect or separation from others that occurs. The participants' descriptions reveal a strong sense of isolation, in that many of the women chose not to

tell their partners, friends or family members straight away, needing time to process their diagnosis and its implications first. Many of the women describe a time where they isolated themselves, withdrawing from their relationships. They speak about spending a great deal of time in their bedrooms, crying alone, and not sharing their worries with anyone else. This is clear in R's comment: "…and I feel scared…and it was hard to be alone…I don't know…how I coped…I don't know, really…because sometimes when I was alone I would just cry a lot…a lot". Many of the women described needing time alone to think, mourn and process the news before being able to tell anyone else.

This initial withdrawal from relationships is also associated with a withdrawal from life. Many of the participants describe a feeling of being disconnected from life. Being confronted with the knowledge that they have contracted an illness from which many people have died causes them to confront their own mortality and the inevitability of their own deaths. For a time this seems to disconnect them from life and even the wish to live, as can be seen in T's words: 'I was thinking maybe to give up on life'.

Thus, the initial HIV positive diagnosis signals the call to begin the 'Hero's Journey' and could be considered a Separation from all that was familiar and understood about themselves, their relationships and their view of life. The initial denial due to the enormity of the emotional experience can be considered a walling off of the inner experience of the self or a separation from aspects of their authentic experience of themselves. According to Horney (1952) alienating oneself by walling off inner experiences can exacerbate feelings of despair and hopelessness. Hence, the initial denial experienced by the participants can be seen to contribute to the initial feeling of disconnection or separation.

The fact that the participants come from a culture that is considered to be collective suggests that the self and relationships with others are inextricably linked. Hence, the disconnect from themselves and from others that the women describe are inter-related. In each story that was told about the process of discovering herself to be HIV positive and the process of not coping and then eventually coping after this, each women spoke about

the impact that the HIV positive diagnosis had on her identity and sense of self and the changes it brought about in her relationships. They described a great deal of internal conflict or distress and feelings of ambivalence. Hence, the disconnection or separation creates a space for change or 'generativity' (Schneider, 2003). In other words, the HIV-positive diagnosis creates a need for change in the way the women view themselves, their relationships and the meanings which they attribute. The diagnosis and its ensuing isolation appears to create a tension between the women's previous experience of their selves as being interconnected with others and their new sense of isolation and separateness. This tension that is set up between the 'self as individual' and the 'self as other' is described by Manganyi (1981):

> When the chips are down, individuals as well as nations become introverted like the text-book adolescent because they require an inner sense of direction. A preoccupation with identity during moments of crisis in a life history and in history are of significant diagnostic value. This introversion and preoccupation with distinctiveness is not in any way a spurious manifestation. It defines identity for us for it tells us forcefully that identity, as an attribute either of individuals or groups, thrives on exclusion. In the preceding statement we have come face to face with a paradox that is of unusual social significance. The individual whose identity is well-articulated must necessarily lose some of his appreciation of the value of others since his distinctiveness thrives on exclusion (p. 66).

Thus, it appears as if the HIV-positive diagnosis sets up a particular situation in which the value of others becomes temporarily secondary to the value of self. The need to confront one's own mortality seems suddenly to highlight an existential aloneness (Moustakas, 1996) in the world that causes an absorption with the self as individual. The isolation of the experience of receiving an HIV positive diagnosis may also be highlighted by the feeling of disconnection from others that fear of stigma and rejection creates.

Another aspect of the decision to not disclose their HIV-positive status to their parents or families and to separate themselves from their parents and families, is for fear of tainting the family with their shame. Carrying the secret of their illness alone, highlights for them their own "distinctiveness", which leads to the paradoxical situation described by Manganyi (1981) where the 'identity crisis' and ensuing self-reflection and sense of exclusion can lead to a better articulated identity or clearer sense of self. The inner preoccupation created by the sense of isolation appears to create a space for these women to more fully explore their inner worlds. Although painful, they are given the opportunity to confront and integrate aspects of themselves that were formerly denied or repressed.

According to Kaplan and Sadock (1998) identity problems are most often multifactorial and include feeling alienated from family members and experiencing a large amount of turmoil. Thus, the experience of feeling disconnected from themselves that the participants describe seems to be related to their former sense of self being forever changed by the HIV positive diagnosis. Their relationships and hence, who they are, has changed and this loss of who they formerly were leaves the participants with a lack of an integrated sense of self. A close link between this lack of an integrated identity and constant feelings of loneliness is documented by Moustakas (1996).

According to Kaplan and Sadock (1998) "Conflicts are experienced as irreconcilable aspects of the self that the [person] is unable to integrate into a coherent identity" (p. 1263). This statement highlights the role that splitting plays in the participants' fragmented sense of identities. By separating the negative and positive aspects of themselves they avoid the ambivalence associated with internal conflict, but leave themselves fragmented without an integrated, coherent sense of self.

However, splitting and denial are not always detrimental and Klein (1946) and Steiner (1990) both speak about healthy splitting that allows for temporary protection of the good object. By keeping aspects of the self separate, space is made for creative 'generativity', allowing new perspectives to surface in psychological experience (Schneider, 2003).

However, the aim is for these parts to be integrated eventually. According to Bion (1962) the process of integration toward experiencing oneself as a whole and separate person is never straight forward and tends to move in a backward-forward fashion. The goal is for a balance to be achieved between mature ambivalence and healthy but primitive splitting. These two then balance and preserve each other and 'wholeness' is prevented from becoming static. According to Jung (in Mattoon, 1981) the opposite of a flow of energy is entropy, which is a static condition when there is no difference in potential and, hence, no psychic energy – a state that occurs in physical and psychic death. "A condition of perfect harmony is … static. Thus, a mature personality, in Jung's view, is one that is in the process of development, not one that is in perfect balance" (Mattoon, 1981, p.108). This emphasis on a continual process of development highlights Jung's view that development of the mind is lifelong (Mattoon, 1981, p.11).

So, while the sense of disconnection and struggle with identity precipitated by an HIV-positive diagnosis that the participants' describe can be likened to the initial separation in Campbell's (1949) Hero's Journey or the initial stage of Jung's (1933) individuation process, the experience can be related to Kubler-Ross' (1970) first stage of grief, namely denial and isolation.

It is important to note that Jung's (1933) individuation is a process that can occur a number of times in an individual's life. While according to most psychodynamic literature, individuation is described most commonly as occurring initially in infancy, within the mother-child relationship (Winnicott, 1960b) and during late adolescence into adulthood, according to Jung (1933) individuation can occur throughout the life stages. According to Jung (1933) individuation entails an initial realization that the self is divided, and then a process of reintegration of the various parts towards a sense of wholeness. Hence, it can be described as a series of disconnections and reconnections. Although this quest for wholeness is usually reserved for the second half of life, the experience of receiving an HIV-positive diagnosis appears to shatter these women's previous conceptions of self and create a premature need for these women to reintegrate their sense of themselves.

Mudd (1990) suggests that Jung's persona, and its fraternal twin, the shadow, and Freud's constructed conscience, the superego, are all symbolic of the ego's struggle with the paradoxical nature of the self and the light and dark of life and death. Mudd (1990) suggests that the balance of the psyche, or Jung's transcendent function is based on the archetypal experience of living through the threat of physical death. Manganyi (1981) supports the notion that at its core the experience of the divided self is related to confrontation with our own mortality:

> …alienation as a contemporary reality is being recognized increasingly as a fundamental problem of human existence. This insight, in its psychological form at least, recognizes the profound divisions in the personality of modern man and takes the divided self as the starting point of any significant study of the human condition. The divided self is a product of the human condition. The divided self is a product of the human need for repression and in its most recent and radical formulation, this insight says that repression is in service of the ego and its terror at the prospect of death (p. 122).

Jung saw the individuation process as divided into two main stages. In the first "a conscious ego perspective is separated from the individual's originally unified, but unconscious experience of life" (Battista, 1979, p. 115). The participants' description of a sense of disconnection from themselves, others and life after receiving their HIV positive diagnoses could be understood in terms of this statement as a sudden separation from their unconscious experience of life. This separation, according to Campbell (1972) in his 'Hero's Journey', is:

> the 'awakening' of the self no matter what the stage or grade of life, the call rings up the curtain, always on a mystery of transfiguration – a rite or moment, of spiritual passage, which

when complete, amounts to a dying and a birth. The familiar life horizon has been outgrown; the old concepts, ideals and emotional patterns no longer fit; the time for the passing of a threshold is at hand (p. 51).

Thus, in terms of Campbell's (1972) 'Hero's Journey', the participants' need to confront death through the realization of their own mortality that an HIV-positive diagnosis entails, is represented by a crossing of the threshold and symbolizes facing all that is feared in order to live again.

7.2.3. Initiation: Anger, bargaining and depression

The next phase of the journey is Initiation, which is described by Campbell (1972) as follows:

> Once having traversed the threshold, the hero moves in a dream landscape of curiously fluid, ambiguous forms, where he must survive a succession of trials. This is a favourite phase of the myth-adventure. It has produced a world of literature of miraculous tests and ordeals. The hero is covertly aided by the advice, amulets, and secret agents of the supernatural helper whom he met before his entrance into this region (p. 97).

To achieve wholeness, the conscious decision to cross the threshold needs to be made (Johnson, 1997). This crossing of the threshold in the lives of these women can be seen to be the decision that is made to 'really know and understand' (Bion, 1959) their experience. Instead of remaining in denial, these women begin to confront the overwhelmingly painful feelings associated with their diagnosis. The coping styles of behavioral and mental disengagement (Carver et al, 1989) that were utilized in the earlier stages of coping are gradually given up and the women begin to confront their feelings.

As the initial shock and disbelief begin to pass, many of the women describe a time of ruminating over the diagnosis, a time when they "think too much". While much of this ruminating is filled with thoughts of fear around their own possible deaths, these thoughts seem to be accompanied by feelings of intense anxiety and anger towards partners and God for letting this happen to them. This time is also filled with emotions like regret and guilt towards children and partners. Hence, this stage of the Hero's Journey appears to be one where these women oscillate between the paranoid-schizoid and depressive positions (Klein, 1946), in a slow progression from a state of unintegration toward a more continuous experience in the depressive position.

It is important to note that Jung's (1933) process of individuation in adulthood starts during early adulthood, during which time the child is transformed into an adult through separation from their family as an independent person. This initial process involves finding a place for oneself in society and accepting some social role or collective identity. "This defensive, yet adaptive, role of the individual is called their persona" (Battista, 1979, p. 116). Jung (1933) uses the metaphor of morning and afternoon to describe the first and second stages of his individuation process, which he relegated to the early and late stages of adulthood respectively: "The significance of morning undoubtedly lies in the development of the individual, the propagation of our kind and the care of our children. This is the obvious purpose of nature" (p. 112).

Once this has been achieved i.e. the persona has been established and the individual ego has become consciously separated from its self by identifying with a collective or social role, the first stage of the individuation process is complete. Through the stories of the women, it can be seen that they were already engaged in this stage of individuation. All of them had established roles for themselves as adults that involved work of some kind, roles as wives or partners, roles as mothers and roles relating to their families of origin. For many of them these roles within their families, according to cultural norms, involved care-taking. According to Jung (1933) there is then normally a gradual movement into the second stage of individuation, however, for these women, the movement into this

second stage of individuation tended to be rapid, due to the shock of their HIV-positive diagnosis.

In the second stage of individuation the process reverses. During this stage of individuation the aspects of the self that were sacrificed in order to establish a social identity need to be confronted and integrated. Unconscious complexes play an important role in this reintegration process (Battista, 1979). This stage involves confronting one's persona or adaptation to life and becoming ready to give up one's protection and relate more as themselves. "When this confrontation is successful, these persons will feel more natural in their social functioning" (Battista, 1979, p. 117).

Writing about this stage of individuation from a Western perspective, Battista (1979) states: "It is as if the individual's assertion of itself as a fully conscious, independent person motivated solely by its own wishes, wants and desires activates the compensating images of the second movement of the individuation process" (p. 116). He explains Jung's (1933) idea that the second stage of individuation entails the opposite of the first stage. While in the first stage the individual initially separates from family, establishing herself as separate and independent and rather connects to a larger framework of expectations, finding a role within society, the second stage involves a separating from society's views and an inward-turning that allows for connection with the self and with humanity as a whole, on a more collective level. However, when applying the notion that the second stage involves a reversal of the first stage to African culture, there are significant differences that need to be taken into consideration. Individuation from families does not seem to follow the same process in African culture, which suggests that for these women the first stage of Jung's (1933) individuation process, the establishment of a place for themselves in society, would involve them taking on a culturally prescribed care-taking role in their families, such as caring for parents, siblings and other extended family. Hence, for these women, the reversal of this in the second stage of individuation, seems to be an emphasis on separation and on themselves as separate. This idea will be explored throughout this discussion.

According to Kubler-Ross (1970) when denial ceases, it is replaced with anger, rage, envy and resentment. Once the initial shock of the diagnosis had worn off, many of the women interviewed reported a difficult time, where feelings of anger and shame were present. Kubler-Ross (1970) states that during the anger phase of mourning the individual's God is often a target of feelings of rage and many people feel that they have been unfairly treated and/or abandoned. Many of the women in this study reported these feelings towards God and while some reported praying for help with their feelings, others reported a time where they no longer went to church.

In many cases, the anger that these individuals feel is directly linked to their suffering and the perceived unfairness of their situations, however in some cases, it may be linked to previous unresolved anger and resentment from their lives (Kubler-Ross, 1970). The feelings of anger that the women reported feeling towards partners and other family members can be viewed within the context of Jung's individuation process as the beginnings of the confrontation with the persona. For many of these women, the HIV-positive diagnosis that they receive jolts them from their mostly 'unconscious experience of life' (Battista, 1979) and the anger and rage that they feel could be seen to be part of a process of re-negotiation of relationships, and the self in relation to these relationships. Moore (1992) states that anger as an emotion is useful in helping to define and redefine boundaries between ourselves and others. The anger that these women feel causes them to begin to re-evaluate their relationships and the roles that they play within these relationships. According to Winstead, Derlega, Barbee, Sachdev, Antle & Greene (2002) "individuals living with HIV, besides having many personal concerns…grapple with concerns about the state of their relationship with families of origin, children, friends and intimate partners" (p. 180). Many of the women in this study reported a new emphasis in their minds as to how much they give to others and how much they receive. Many reported feelings of anger at a perceived sense of unfairness in many of their relationships and a time of needing to re-evaluate their caretaker roles, due to the increased pressure they now felt to take care of themselves and their children. Hence, this questioning of their culturally prescribed roles can be viewed as a confrontation with their individual personas. In the study conducted by Koopman et al. (2000) that found a relationship

between attachment style and perceived levels of emotional distress in HIV positive people, it was stated that interventions aimed at assisting HIV positive people to examine their attachment styles could assist in alleviating levels of distress:

> For example, an HIV positive woman who realizes that she has a highly anxious attachment style may then be able to identify situations in which she is trying too hard to please other people in order to feel lovable. Such insights could help her experience less stress. Her stress could be alleviated due to realizing that she is investing unduly in relationships with rejecting or overly critical individuals who do not provide validation of her worth. She could also reduce her stress in interpersonal relationships by reinterpreting social distance more positively as providing opportunities to rely on her own sense of self-worth, rather than as a sign of rejection. Also, by becoming more selective about pursuing closeness to other persons, she may experience less stress as a result of avoiding situations in which other persons react negatively to her intrusive attempts to achieve and maintain undue closeness (Koopman et al., 2000, p. 670).

It appears that the women in this study, through confronting their feelings about themselves and their feelings about their relationships with others, begin to gain greater levels of awareness about their own attachment styles and begin to renegotiate their ideas about relationships, as suggested by Koopman et al. (2000).

However, it is also important to note that feelings of anger towards the self and others are also strongly correlated with feelings of shame. Lewis' (1987) model of shame relates shame to helplessness, anger at others, anger at self, feelings of inferiority and self-consciousness. The feelings of anger that many of the women report seems also to be the beginnings of their confrontation with their sense of shame around being HIV-positive. This confrontation seems to be an important step in the process of coping with HIV due

to the fact that studies have found that shame is also associated with a reduced sense of self-efficacy (Baldwin et al., 2006). These women's attempts to grapple with self-efficacy or a sense of regaining mastery and control over their lives can be seen in Kubler-Ross' (1970) next stage of mourning, namely bargaining.

Bargaining was evident in the stories of these women and while bargaining can be seen as an attempt to deny the reality of their HIV-positive status, it can also be viewed as an attempt to hang onto life, or in the case of these women, as the beginnings of the will to reconnect to and participate in life once again. The bargaining phase seems to be a part of these women's processes of re-negotiating their relationships with God and Life. According to Kubler-Ross (1970) bargaining usually involves a promise of 'good behaviour' in return for more time and is really an attempt to postpone. Many of the women reported praying to God to let them survive long enough to raise their children, which despite being an indication of one of the biggest worries for these women, could also be construed as striking a bargain with God: 'if you give me more time, I will be a devoted mother'. The fact that many of the women related their request to the welfare of their children suggests that this attempt to bargain may also be related to feelings of guilt that these women experience towards their children. According to Kubler-Ross (1970) it is important to understand that sometimes, underlying a bargain that is made is guilt or irrational fear.

Bargaining can also be viewed as an attempt by these women to re-negotiate their sense of control over their lives. Being given an HIV-positive diagnosis was described by many of the women as shocking, leaving them with a sense of helplessness and lack of control over their lives. The consequences of living with HIV, such as the loss of their previous sense of self and security in life, the loss of partners, children and other family members, the loss of financial stability and, in some cases, the loss of their own health also seemed to contribute to these women's sense that their lives were no longer under their control. According to Rabkin, Williams, Negebauer, Remien, & Goetz (1990) in their study on coping in HIV positive men, a sense of perceived control is associated with an improved quality of life. Taylor et al. (2000) have found that experiencing a sense of

personal control and having optimistic beliefs can function as protective factors for psychological and physical health and according to Ryan and Deci (2000) perceived control could even be considered to be an innate need. While this lack of perceived control may have contributed to these women's feelings of sadness, despair and depression, a part of the process of coping for many of these women was re-establishing a sense of control over their lives.

Rotter's (in Compton, 2005) idea of an internal versus an external locus of control is useful when considering the situation of these women and can be linked to the aspect of the Jungian individuation process which entails confronting one's shadow. Throughout the stories of these women, many of them seemed to take pride in their strength, in their ability to survive hardship, in their resourcefulness and in their ability to look after others and manage family situations. While we might speculate that this may have resulted from the stories of extreme hardship and deprivation that characterize many of the women's early childhoods, in which they were required defensively to become precociously responsible 'parental children', this pride in their strength implies a strongly internally located locus of control. This suggests that the shadow for many of these women is a sense of themselves as vulnerable, needy, dependent and having no control over what happens to them in their lives. The HIV-positive diagnosis seems to be the crisis that requires these women to confront the more vulnerable aspects of themselves.

For many of these women, the beginnings of the confrontation with their own vulnerability is prompted by physical illness. According to Manganyi (1981):

> The fear of death is experientially and symbolically tied up to the reality of the body. It is for this reason that the denial of death is first and foremost a denial of the body and through symbolic elaboration, man's body has come to stand for death and finitude. The 'curse', therefore is…man's creatureliness – man's body (p. 121).

The vulnerability of their bodies seems to leave many of the women no choice but to confront their HIV-positive status and the implications this has for their lives. Many of the women reported becoming ill as having been an extremely frightening experience, where they experienced a sense of having no control over what happens to them. This lack of control over their bodies seems to bring the issue of control, generally in their lives, into focus.

For these women, the tension between the opposing poles of strength and vulnerability in relation to control is difficult to manage. While maintaining an internal locus of control in relation to having contracted HIV resonates with these women's worldviews or internal structures and allows for a sense of predictability and security in their lives, it also entails self-blame, shame, guilt and a sense of being punished for having done something in order to deserve the HIV. In contrast, shifting to an external locus of control in relation to their HIV allows for the blame to be apportioned elsewhere, namely on a partner or God, however, this then entails confronting feelings of betrayal, abandonment and rejection in relation to the other.

This process, initially, is reminiscent of Klein's (1946) description of healthy splitting that is utilized to keep the good object safe. These women seem to oscillate between experiencing the 'badness within' in order to avoid having to attribute it to others and confront their subsequent feelings towards them, and then experiencing the 'badness without' through the projection of their rage and aggression onto others, resulting in a sense of a persecutory relationship. This is evident in the women's reports of feeling punished by God. C's comment: "…in the first I was not strong…I was crying all the time and I was asking God why he make my husband sick…" shows how her initial feelings were that of helplessness and a sense of being punished, but her later feelings: "…I give it all to God and now sometimes I am happy…sometimes you got the worry…but sometimes not…God he help me…in my life…the church first gives me hope…I am strong in the church" seem to reflect a sense of being cared for and a more balanced, integrated view.

Later in the process, having considered and experienced both an internal and external locus of control, these women manage to find a balance between them, negotiating the sense of vulnerability it leaves them feeling when they attribute negative events externally, and the sense of responsibility they feel when internal attributions are made. These seem to link to Winnicott's (1960b) notion of object relating, which is said to happen later in the holding stage between mother and infant, and Klein's (1946) description of the integration of good and bad in one whole object that is required to reach the depressive position. It appears as though these women, in the process of moving from a vulnerable, temporary paranoid-schizoid position, toward a more integrated depressive position employ normal splitting to ward off destructive impulses and perceived threats to their relationships, in order to preserve their relationships (or the good objects contained therein) and the gradually, as the ego strengthens, they become more able to tolerate ambivalence.

In general, the literature around locus of control suggests that having an internal locus of control is associated with a number of positive outcomes (Lefcourt, in Compton, 2005). This finding can be related to the findings of studies on personal control (Peterson, in Compton, 2005), which suggest that personal control is the belief that a person can make choices, cope with the results of these choices, and then learn from the outcomes of the choices in order to "maximise good outcomes and /or minimise bad outcomes" (Peterson, in Compton, 2005, p. 49). The learning from the outcomes of choices is often linked to the process of finding meaning in experience (Compton, 2005). Hence, the feelings of guilt and regret that many of these women report, which appear to represent a more internal locus of control, may also be an indication of a shift towards the depressive position.

Rothbaum, Weisz and Snyder (in Compton, 2005) studied religious beliefs and found that a belief that God holds control over people's lives is a form of secondary control rather than an example of an external locus of control, which is why religious beliefs have been found to be associated with more positive outcomes. According to Compton (2005):

> With secondary control, people can gain a sense of control by associating themselves with a person, philosophy, or system that they view as more powerful than themselves. Therefore, in a somewhat paradoxical way, it is also possible to feel in control by consciously and deliberately giving up control to a more powerful force, such as God. In other words, one can gain a sense of control by knowing that it was a conscious choice to relinquish control (p. 49).

Thus, when considering C's comments on the previous page, the fact that these women are able to integrate their negative and positive feelings toward God allows them to have a relationship with a being whom they feel can protect and assist them.

Thompson, Nanni and Levine (1994) also found that in coping with HIV, it is especially important for people to distinguish between areas of their lives that are under their control and the areas that are not. Thompson et al. (1994) found that individuals who were able to distinguish between these areas and who felt that they could cope with the consequences of HIV, which represents consequence-related control, rather than feel they could control the HIV itself, which represents central control, had higher levels of psychological well-being. This ability to distinguish the limits of one's control represents an important acknowledgement of areas of vulnerability and a coming to terms with this.

As described above, these women's confrontation with the more vulnerable parts of themselves represents another crucial stage in the second stage of Jung's individuation process, which is the confronting of the shadow or rejected, unconscious aspects of the self. The process of confronting these aspects of the self which have been split off and rejected from consciousness is often facilitated by realizing that these aspects are often projected onto people or institutions around one. It could be viewed, in part, that the care-taking role that many of these women fulfill, is due to their projection of their own vulnerability, which they experience as unbearable, onto others whom they then perceive as weak and dependent and for whom they then care. The process of dealing with their

own HIV-positive status entails a confrontation with their own sense of vulnerability and their need for support and care. This confrontation then allows for an integration of this shadow aspect of themselves and a balancing of their roles as care-giver and care-receiver.

"In order to integrate these bad or negative aspects of one's self, individuals must learn to see their positive side, how they are perversions of a positive strength that the person is in need of, or come to understand that they are rooted in some fear of proceeding further in their self-confrontation" (Battista, 1979, p. 118). This process is evident in many of the women's new-found emphasis on caring for themselves both physically and psychologically. Many of the women related stress to poor health and spoke about the need to look after themselves. In this way, they seemed to be able to legitimize and integrate their own vulnerability.

It is important to note though, that the process of individuation is seldom simple and that Jung (1933) regarded it as a life-long process, believing that the tension moving between various polarities or aspects of the self continues for as long as the individual exists. As mentioned previously, Jung considered a mature personality to be one that is in the process of development, not one that is in perfect balance (Mattoon, 1981). Hence, certain aspects of the self are integrated more easily than others and for these women, there will always exist certain aspects of their shadows that are not integrated. An example of this in many of the women is their sense of shame. For many of them it remains a painful part of their experience of themselves that they need to defend strongly against feeling. Defenses like splitting and projection are used by many of the participants in order to avoid fully experiencing their own sense of shame. As mentioned by Rohleder and Gibson (2006) the projection of difficult feelings associated with being HIV-positive are often projected into those people who do not yet know their status. This was also evident in this study, with some of the women commenting that when at the clinic, in order to defend against the shame that they feel while waiting in the "HIV" queue, a great deal of the conversation deals with those who shame them, namely those in the non-HIV queue. These people are spoken about in derogatory and devaluing ways, as

being people who are ignorant about HIV and people who are more at risk because they don't know their status. While this is clearly a projection of their own vulnerability and sense of shame, including the rejection that accompanies this shame, these women seem to regard those that don't know their status as 'not belonging' to the group that do know. This process can also be understood in terms of Lyubomirsky and Ross' (in Compton, 2005) studies on comparing the self to others, which showed that people who tend to use downward comparisons more often tend to be happier. However, while the need to defend against such unbearable feelings is understandable, the process highlights Jung's (1933) emphasis on the importance of heightening the awareness of the personal 'shadow' or darkness, as it can help people understand others' shadows, which can prevent the 'we-they' mentalities that can produce hostile and punitive attitudes toward people outside a person's own social group. Considering the stigma and fear surrounding HIV/AIDS and the consequences of this stigma for people with the disease, the relevance of confronting the shadow becomes one that needs to happen on a societal level. Manganyi's (1981) views on stigma and discrimination also highlight the relationship between a split sense of self and 'othering' and oppression: "We need to recognize that oppression breeds insecurity and a dissipated sense of self-hood, and leaves psychological scars of varying degrees of chronicity" (p. 102).

According to Jung (1933) the third part of this second stage of individuation involves confronting the contrasexual elements of one's self i.e. the anima or animus. According to Battista (1979): "These complexes [anima and animus] are more unconscious than the shadow because they represent latent or unrealised aspects of the person which have never been conscious rather than elements which were rejected or repressed from consciousness" (p. 118). According to Jung (1933), the process of confronting the anima or animus is about discovering and integrating characteristics of the opposite sex that were formerly repressed" (p. 110). Jung (1933) speaks of the need to embrace these opposite qualities and incorporate them into the personality in order to move towards a new sense of wholeness. While Jung (1933) described that the majority of men and women tend to be confronted with their anima or animus through the process of aging,

where bodily changes start to reflect a loss of masculinity or femininity, for the women in this study, the confrontation with their animus tended to happen in different ways.

It is important to note that Jung's (1933) concepts of anima and animus are thought to represent the collective cultural notions of masculinity and femininity, hence it is important to consider the African notion of animus within the cultural representations of masculinity, namely authority, dominance, control, provision and protection of family, and the right to speak out. These women's confrontation with their animus can be seen to be starting in many of the women's stories in the form of their shirking traditional female traits, such as submission. For many of the women, speaking out or being 'cheeky' was regarded as extremely important. Jung (1933) speaks about the confrontation with the animus as a transformation in that women become more masculine in their thinking and being in the world: "…one can observe women in these self-same business spheres who have developed in the second half of life an uncommon masculinity and an incisiveness which push the feelings and the heart aside" (p. 110). The taking up of the traditionally masculine role of providing for and protecting their families is evident in many of the women. For some this is a choice and they are even able to relate how the HIV-positive diagnosis 'saved their lives' as it motivated them to stand on their own two feet and rely on themselves. For others, the taking up of this role is through necessity due to the loss of their spouse. However, as Jung (1933) states, it is often through the failure of the partner or husband to live up to the individual's expectations that prompts an awareness of the animus that the individual projected onto them.

Jung (1933) believed that the purpose of the second half of life is to individuate further. While the first half of life holds the challenge of individuating from family and becoming a part of society, conforming to society's expectations, the second half involves individuating from these expectations and moving toward a paradoxically more separate sense of self that is connected to a larger sense of collective meaning. Jung (1933) felt that this could be achieved through confrontation with the Self.

Once a person has confronted and integrated the persona, shadow and anima or animus, the various parts of the personality have been realised. The final part of this second stage of individuation is then for the individual to confront the Self, which is an aspect of psychological life that according to Battista (1979) "transcends any individual differentiation or limitation" (p. 119). During the second stage of Jung's (1933) individuation process "the individual ego is consciously reintegrated with this unified state, called the self" (Battista, 1979, p. 115). For this integration to occur, "the aspects of the self which were denied, repressed, projected or left unexperienced must be confronted and experienced" (Battista, 1979, p. 115). Thus, in order to achieve a new integration of self, painful aspects of these women's experiences need to be confronted and felt and the losses that this entails need to be mourned. This process can be likened to an ongoing series of conscious voluntary psychological deaths (Mudd, 1990). Thus, the experience of 'going underground' that is associated with Initiation, the second stage of the 'Hero's Journey', could be likened to the confrontation with death, where the denial lessens and the internal conflict or confrontation with the persona and shadow is faced.

The beginnings of the final stage of Jung's individuation process can be seen in Kubler-Ross' (1970) stage of grieving, depression. According to Kubler-Ross (1970) when denial of the gravity of their situation is no longer possible, the numbness, anger and rage are eventually replaced by a sense of great loss. This loss may take many forms according to the circumstances of the individual's life and their illness, for example, many may mourn the loss of their beauty, their physical strength, their job, their ability to care for their children etc. This mourning could be viewed as the beginnings of the confrontation with Jung's (1933) concept of the Self. These women are confronted with the challenge of mourning and letting go of the self that was and embracing a new sense of self that holds new meaning.

Kubler-Ross (1970) writes about two distinct forms that this depression takes. The first is a reactive depression that involves past and recent losses that are normally accompanied by guilt and shame, and the second form of depression is more related to a

sense of sadness and acceptance. These two forms of depression can also be understood in terms of the paranoid-schizoid and depressive positions. According to Winnicott (1954) trauma and other life experiences can evoke a reworking of the depressive position (Winnicott, 1954) and this then influences how mourning is managed:

> Melanie Klein's work has enriched the understanding Freud gave us of reaction to loss. If in an individual the depressive position has been achieved and fully established, then the reaction to loss is grief or sadness. Where there is some degree of failure at the depressive position, the result of loss is depression (p. 275).

According to Freud (1917) when a loss is experienced, the object lost is introjected. Internally it is subjected to the more persecutory forces i.e. anger and hatred. If the depressive position, according to Klein (1935) was not yet achieved, and the individual is not yet able to tolerate both negative and positive feelings towards an object, the balance of forces internally is disrupted and an overall internal deadening produces a depressed mood. This depression, according to Winnicott (1954), can be healing as it provides defences and time against an overwhelming pain, allowing for the loss to be more slowly worked through. "In these and other ways mourning is experienced, and worked through, and grief can be felt as such" (Winnicott, 1954, p. 275). Hence the working through of Kubler-Ross' (1970) depressive stage of mourning seems to facilitate the movement of these women towards the depressive position.

While the HIV-positive diagnosis seems to be the catalyst for many of these women to embark on this Hero's Journey, ill-health, lowered CD-4 counts and hospitalizations seem to mark this final confrontation with the ultimate separation. The role of the body in the confrontation with death is explained by Manganyi (1981):

> In considering the problem of man's alienation and the character of the 'divided self' (Laing, 1959), one needs to bring into prominence the extent to which man's body is an eternal problem

to him…the body, by being an important axis of the existential dualism, creates tensions in the life of individuals. Self-consciousness incubates terror and dread, specifically in respect of a full recognition of the cynical reality of the human body. It is the body, together with the symbolic elaborations related to it which makes death such an immediate and excruciating human reality…the givenness of the individual's life involves the contradictory realities of the finitude of the body and the limitless horizons of self-consciousness and man's capacity for symbolization (p. 107).

The psychic 'death' experienced during the 'Hero's Journey', spoken of by Campbell (1972) is a theme explored by many theorists. Freud first spoke of it as the 'death instinct'. Since then it has been implicated in pathology as well as in the process of individuation, where its motivating role is vital. Jung (1912) touched on the fear of death as an interfering factor in the process of individuation stating that neurotic individuals who cannot leave their mothers have good reasons for not doing so and it is ultimately the fear of death that holds them there. However, it has also been considered an essential motivating factor in the individuation process. In Campbell's 'Hero's Journey', the protagonist must face the ultimate fear in order to transform. Mudd (1990) explains the process in which death is a transforming factor:

Our commonplace, everyday anxieties concerning any form of risk, failure, need or limitation, all of which inhabit the darker reaches of the self, can be traced ultimately to the ego's most dreaded fantasy: its own extinction…Despite the ego's horror in the face of its own mortality, death has tremendous psychological utility. It is in reality the primary catalyst for individuation and offers us the opportunity to enter our own destinies by passing through the ego's illusions into the ineffable essence of human

This confrontation with death is a theme that runs throughout these women's Hero's Journeys. The confrontation begins with feelings of horror and shock, which seem to prompt a temporary regression into the paranoid-schizoid position. Splitting and projection are evident and Kubler-Ross (1970) writes about the fact that dying is almost always perceived as an attack from the outside of the self and that "…death in itself is associated with a bad act, a frightening happening, something that in itself calls for retribution and punishment" (p. 3). Many of the participants described thinking that they were going to die accompanied by intense feelings of fear soon after diagnosis. They also reported that their initial attempts to make meaning of this included a sense of being punished. There is a loneliness experienced in this initial stage of the confrontation with death that is described by Moustakas (1996) as loneliness anxiety, which is the loneliness of self-alienation and self-rejection. Moustakas (1996) considers this to be a vague and disturbing anxiety: "…in loneliness anxiety man is separated from himself as a feeling and knowing person" (p 24). Hence, this could be considered the loneliness associated with the paranoid-schizoid position.

Hence, throughout the course of life individuals experience separations and loss that in essence mirror the loss associated with their own eventual death. How these separations and losses are managed and integrated into a new sense of self could be said to be determined by the degree of resilience that the individual innately possesses. However, according to Folkman and Lazarus' (1988) concept of positive coping, how the separations and losses are managed throughout life could also be said to develop an individual's capacity to cope with further losses. Kubler-Ross' (1970) study on terminally ill patients supported this notion. She also found that how people managed their grief depended on how they had managed previous hardships in their lives:

> Since in our unconscious mind we are all immortal, it is almost
> inconceivable for us to acknowledge that we too have to face
> death. Depending very much on how a patient is told, how much

time he has to acknowledge the inevitable happening, and how he has been prepared throughout his life to cope with stressful situations, he will gradually drop his denial and use less radical defense mechanisms (p. 37).

Hence, as can be seen in the above statement, as the Hero's Journey progresses, the need for the more primitive defenses of splitting, denial and projection gradually decreases. As the experience of loss is mourned and processed, integration occurs and there is a move towards the depressive position. This seems to be essential in order for the last stage of Jung's (1933) individuation process, the confrontation with the Self, to occur. According to Winnicott (1960b), "death has no meaning until the arrival of hate and of the concept of a whole human person" (p. 47). Only when a person can be perceived of as alive and separate, can an individual begin to contemplate the true meaning of death and the separation that it entails. The loneliness experienced by the individual in this stage is considered to be existential loneliness, which is necessary for a person to become fully aware of himself as an isolated and solitary individual (Moustakas, 1996). Existential loneliness is considered to be an unavoidable and even valuable element of being human. Wolfe (1941) discusses the inevitability of real loneliness as a part of genuine experience and an intrinsic condition of existence. He believed that it is necessary because out of these depths of despair and feelings of complete impotency comes the discovery of unique ways of being aware and expressing experience.

Facing death or dying is essentially a process that is done alone. Despite support from others, the thought of one's own death is a frightening, lonely experience. Hence, a part of these women's process of truly confronting their own mortality is the ability to endure the feeling of being alone in the world. According to Winnicott (1958) the capacity to be alone is a highly sophisticated phenomenon of early life, which "is the foundation on which sophisticated aloneness is built" (p. 30). Winnicott (1958) states that the capacity to be alone is founded on a paradox, which is that the capacity to be alone develops in the presence of another. According to Winnicott (1958):

Although many types of experience go to the establishment of the capacity to be alone, there is one that is basic, and without a sufficiency of it the capacity to be alone does not come about; this experience is that of being alone, as an infant and small child, in the presence of the mother…the capacity to be alone depends on the existence of a good object in the psychic reality of the individual (p. 30 - 32).

Winnicott's (1958) concept of the capacity to be alone can be extrapolated and it can be said that only if there has been good-enough parenting can the capacity to be alone develop, and further, if there has been good enough parenting then it can be said that there exists a self that can fully understand death and who is ready to die.

As mentioned previously, in the literature review, Silverman (1999) regards grief as occurring within a relationship. Mudd (1990) echoes this sentiment stating: "It is human relationship which provides the sacred space within which we learn to die and which enables the transcendent function to evolve into operational psychological reality" (Mudd, 1990, p. 127). According to Mudd (1990) birth is the initial separation or first 'death' that we experience in human relationship. Battista (1979) writes that according to Jung the interplay between the mother's body and the infant's needs is "deepened and made more complex by the advent of birth and the physical separation of mother and child" (p. 115) and according to Jung (1933), when the initial stage of union between the mother and child is broken by birth the infant is forced to become gradually conscious of itself as separate.

Winnicott's (1960b) theory of early infant development explains in more detail Mudd's (1990) notion that birth and the subsequent initial realization of separation are the first 'death' that we experience in human relationship. According to Winnicott (1960b) when interruptions are experienced in the holding environment that the mother creates for the child, the child experiences interruptions in their developing 'continuity of being' which slowly allows for the infant to begin to see itself as separate from the other. As mentioned previously, the disconnects that the participants experience in their sense of

self and their relationships post diagnosis is reminiscent of Winnicott's (1960b) description of the initial separation between mother and child, where the child now has to begin to integrate a new and more separate sense of self, much like the participants in this study.

According to Winnicott (1960b) this is a crucial stage in the development from dependence to independence. "This change is closely bound up with the infant's change from being merged with the mother to being separate from her, or to relating to her as separate and 'not-me'". (Winnicott, 1960b, p. 45). In the case of these women, they could be seen to be merged with a certain understanding of themselves, others and life and the separation we see is from this particular understanding. The HIV-positive diagnosis causes the separation and they are now faced with finding a new 'continuity of being' and re-integrating a new and more separate sense of self. According to Winnicott (1960b) this development is related to the phase of 'living with'. While the concept of 'living with' is easily evident in the relationship that these women have with the HIV in their bodies i.e. they have to learn to live with their positive status, according to Winnicott (1960b) the notion of 'living with' others entails a sense of the self as separate from others but with them. This can be conceived of as being these women's negotiation of themselves and their relationships with others in terms of separateness and togetherness.

The tension between these two polarities makes space for thinking about Winnicott's (1958) paradoxical notion that being alone in the presence of the mother allows for the development of the capacity to be alone and the capacity for relatedness. Winnicott (1958) refers to the relationship between the mother and the infant as being significant for the development of ego-relatedness. Sustained relationships require both the ability to 'be with' as well as 'be alone' from time to time. It is the ego-relatedness or ability to hold a positive mental representation of the other when apart that promotes relatedness.

This negotiation seems to be much like Jung's (1933) final stage of individuation, in that what is required is the ability to see one's self as both separate and connected to a greater

collective unconscious. Hence, it can be seen that the capacity to truly confront death requires an achievement of the depressive position, with its ability to tolerate ambivalence.

For the infant, the mother represents life itself and the initial separation evokes a great deal of anxiety. During adulthood, the prospect of separation from life itself could still be construed to be the source of humanity's greatest anxiety. Jung's (1933) theory of adult development describes individuation as a movement towards wholeness that entails a number of disconnections and reconnections, with the last disconnection being from life itself towards a reconnection with the ultimate Self, or all that is. The HIV-positive diagnosis received by the participants in this study catapults them suddenly into the second stage of life where, according to Jung (1933), nearing death calls into question the meaning of society and family and the existence of the self. The aim is to find this meaning, which entails acknowledging and reintegrating all aspects of the self that are lost during the first stage (Jung, 1933). This process is also reminiscent of Winnicott's (1960a) description of the development of a false self in order to protect the true self. According to Winnicott (1960a) when certain of the child's feelings are overwhelming for the caregiver, the child learns that these feelings are unacceptable and they are repressed or relegated to what Jung (1933) terms the shadow. Instead a false self (Winnicott, 1960a) or persona (Jung, 1933) that is perceived to be more acceptable to others develops. In other words there is a "substitution of the gestures of the other for the gestures of the self" (Fonagy, 2001, p. 102). According to Winnicott (1960a) this false self appears real and complies, but is essentially "fragile, vulnerable, and phenomenologically empty" (Fonagy, 2001, p. 102). Winnicott (1960a) theorizes that the purpose of a false self is defense as the false self serves to hide and protect the true self.

Hence, it can be seen that the Hero's Journey is essentially a journey into the self and the monsters that are met are the aspects of the self that are considered unacceptable and shameful. The exploration of these aspects of the self, the recognition that they do in fact hold value and the subsequent integration of these aspects into the self is the purpose of the journey, thus it can be seen that coping with HIV/AIDS for these women is a process

of separation, self-discovery and eventual reconnection with life. Through successful mourning of the losses involved with being HIV-positive, these women are able to reach a place of realization that their Self is in fact Life and connected to all that is. This realization allows them to find new meaning in their situation and the will to reconnect with others and once again, participate in life.

Battista (1979) states: "This confrontation of ego with the self marks the final, deepest and most intriguing aspect of the individuation process. The ego must consciously realise the wholeness of the self, yet in order to do so, it must give up its sense of importance and control" (p. 119). Referring to the experience of the Self, Wilhelm and Jung (in Jung, 1933) state: "It is as if the leadership of the affairs of life had gone over to an invisible centre…and there is a release from compulsion and impossible responsibility which are the inevitable results of participation mystique" (p. 78-79). This experience of 'participation mystique' or sense of connection to God and life and meaning is the prize for having survived the Hero's Journey and this new sense of self is what is taken back when these women return.

Hence, the process of coping with HIV/AIDS seems to entail a negotiation of the self as individual or separate from others and the self as connected to others. The Initiation stage of the Hero's Journey seems to be the time when denial decreases and the women choose to know their experience. The process of going through the painful feelings of anger and depression seems to be what Jung spoke of as confronting the aspects of the self that were formerly repressed. For the women in this study, this seemed to entail a re-negotiation of their sense of self to incorporate into their previously strong, care-taking, self-sufficient ideas of themselves, elements of vulnerability and shame. This necessarily entails a shift in identity, which is what is to be discussed in the next section.

7.2.4. Return: Acceptance and hope

Campbell (1949) describes the stage of Return:

> When the hero-quest has been accomplished, through penetration to the source, or through the grace of some male or female, human or animal, personification, the adventurer must still return with his life-transmuting trophy. The full round, the norm of the mono-myth, requires that the hero shall now begin the labour of bringing the runes of wisdom, the Golden Fleece, or his sleeping princess, back into the kingdom of humanity, where the boon may rebound to the renewing of the community, the nation, the planet, or the ten thousand words (p. 193).

Return is where the hero has survived and must now return to the world he/she knew before, relinquishing his/her powers but keeping some new qualities, with which things are set in order (Lukoff, 1985). This stage symbolically represents the integration of what has been learned into the self and their lives. It represents the process of integration of the self and others, the emergence of a new identity and essentially a new way of being in the world that is more aware and more connected.

This new sense of self is based on the successful resolution of mourning, which according to Freud (1917) allows the individual to take back energy that was invested into the lost object and re-invest it elsewhere. Klein's (1946) notion of the achievement of the depressive position and the mourning and separation entailed in this process can be likened to Kubler-Ross' (1970) final stage of grieving, namely acceptance. According to Kubler-Ross (1970): "We should be aware of the monumental task which is required to reach this stage of acceptance, leading towards a gradual separation (decathexis)" (p. 105). Hence, acceptance can both be viewed as these women's acceptance of the losses that they have suffered and their acceptance of the necessity for a new integration of self.

The stage of return is when these women begin to re-invest this energy back into life. Having confronted unimaginable fear relating to their own potential death and overwhelming emotion associated with this, they have found a way to reconnect to themselves differently, and they are now able once again to engage in relationships and a future for themselves and their children. This discussion will firstly attempt to explore the changes in identity that this process has involved for these women and then the focus will shift to how the energy freed up through the process of mourning is re-invested back into life.

Jung's (1933) process of consciously realising the wholeness of the Self has been called the sublimation of the ego to the Self (Neumann, 1970) as well as the Hero's Journey. Campbell (1956) wrote about the common theme of discovering the Self through confrontation with aspects of the personality which is found in myths from all around the world.

The hero is usually associated with an unusual fate where his task is to do something out of the ordinary. The goal of the journey is to survive a dangerous ordeal "to find the treasure, the ring, the golden egg, the elixir of life – psychologically, these all come to the same thing: oneself – one's true feelings and unique potential" (Sharp, 1998, p. 108). According to Jung (in Sharp, 1998) this journey is analogous to the psychological "attempt to free ego-consciousness from the deadly grip of the unconscious" (p. 110).

This attempt to find the Self can be viewed as an attempt to know one's own experience (Bion, 1962) and is a painful process. It can also be equated with Klein's (1946) move towards the achievement of the depressive position, which is associated with an increasing integration of the self and object relations, in essence, a greater wholeness of the self. However, it is important to note that there is a necessary mourning that has to occur during the achievement of the depressive position and that this is related to separation or differentiation (Winnicott, 1954).

According to the stories of the women interviewed for this study, this separation is different from the initial withdrawal seen in the earlier stages of coping with HIV. While the initial separation could be seen as a denial of loss and attempt to evade 'knowing' their experience (Bion, 1962), this separation seems to be a confrontation with reality and an acceptance of a degree of 'existential loneliness' (Moustakas, 1996).

The confrontation with themselves and their feelings and experiences during the Initiation phase of the Hero's Journey (Campbell, 1972) seemed to cause a re-evaluation or a thinking about themselves and others. According to Fordham (1953) it is the reconciliation of opposites that constitutes Jungian individuation, hence, the Initiation phase of the Hero's Journey entailed for these women an integration of aspects of the self formerly 'unknown' or relegated to the shadow. For these women, this included a process of confronting their true feelings and negotiating dependence and independence.

The confrontation with their true feelings was a painful process for these women and once accomplished resulted in a stronger and more integrated ego. In other words, having survived the difficult process of confronting their painful experiences, many of the women felt stronger and more able to cope with life. Folkman and Lazarus' (1988) study on coping suggested that when cognitive appraisals of negative life events are put into perspective through comparing the event with the perceived abilities of the individual to cope with these challenges, the individual's distress can be mediated. In other words, positive coping is the process through which adaptations that are necessary to cope are made, and through this people become stronger and their general quality of life increases. This is known as thriving, a term which has come to denote the improved physiological and psychological functioning after a person has successfully adapted to a stressor (Epel, McEwan & Ickovics, 1998). According to Turner-Cobb, Gore-Felton, Marouf, Koopman, Kim, Israelski and Spiegel (2002) "…for people with HIV/AIDS, those individuals who are more satisfied with their relationships, securely engaged with others, and more directly engaged with their illness are more likely to experience positive adjustment" (p. 337). Hence, it appears that the ability to confront difficult feelings and remain engaged contributes towards better adjustment.

With regards to the negotiation of dependence versus independence, dependence on society and culture for guidance and ways to think about things was called into question for these women by the stigma held by society around HIV/AIDS. For many of the women, this seemed to start the second part of Jung's individuation process, which entails moving away from a sense of belonging in society to finding their own meanings, which according to Jung (1933) paradoxically connects one to a greater collective.

For many of the women, coping with their HIV-positive status had re-evoked a number of feelings related to their experiences of childhood and many of the stories told related situations of deprivation and sometimes even abuse and neglect, which evoked feelings of fear, persecution, unfairness and loss. Manganyi (1981) writing on the black consciousness movement of the 1970s, has interesting notions that could apply to the resilience exhibited by these HIV-positive women. His statements reflect a sense of overcoming hardship in order to emerge more connected to an authentic self and flourishing. He writes about the need "to outgrow the victim status and offer in its place a consciousness and ethic of hope" (p. 168). He states:

> Now to outgrow the pariah status, the status of being a victim, is to become the rebel who understands his situation more fully for the first time…for us the purgation that accompanies authentic self-knowledge was instrumental in getting us out of the trance of being pariahs and victims…Those with adequate inner resources could now snap out of the trance of the false consciousness and become, through much pain and anguish, the rebels who understand history…[who know]…that self-reliance is the bed-rock upon which psychological liberation is founded – the painful transition from being a victim to being a rebel who understands history…The present and the future are full of challenges to be met and certainly one of these is our responsibility now not to collude in our own victimization…Self-reliance, an inner sense of personal freedom,

constitutes the crest of the wave of creative awareness…We often fail to understand the intricacy of this transformation, this flowering of the self-reliant spirit…a new majesty of spirit invades the rebel's self-hood and urges him on to confirm and validate himself…he invests his energies in resources both within himself and his community and moves out into the social world to create. His rhetoric becomes strident and since the new language is evolved in the interests of clarification, it is part of the total ritual of rebirth…This rhetoric, this new language for new meanings, new truths and experiences, is an important element of the elaborate ritual in the birth of a rebel. It consolidates his psychological and spiritual gains to the extent of enhancing his sense of identity (p. 170 -172).

This shift in identity was evident in many of the women's stories as although many of them continued to meet some of the culturally accepted norms, such as financially supporting their parents and siblings and respecting the wishes of their elders and husbands, many of them spoke about a new-found sense of independence and autonomy and a balancing of the wishes and needs of others with their own. The self-sacrifice encouraged in African culture seemed to be mediated by a need to protect and look after themselves and many of the women related making different decisions based on this shift. Hence these women seem to have found a way to balance their own and others needs within the bounds of their culture. According to Manganyi (1981): "Culture as metaphor, as language, as communication, flourishes only in a climate of freedom – in a climate within which, paradoxically, individual identity is cherished more than collective or group identity" (p. 70).

Autonomy as a concept refers to the ability to make independent decisions about areas which the individual deems to be important (Ryan & Deci, 2000) and has been related to a sense of mastery or competence. Throughout these women's stories, a sense of pride in their independence and autonomy was evident. This could be related to the achievement

of the separation required for depressive position functioning and it is interesting to note that a study conducted by Knee and Zuckerman (1996) found that people who are more autonomous and who did not feel pressure to conform were less likely to use defensive coping strategies, which is considered an important characteristic of the depressive position.

According to Compton (2005) our levels of self-esteem are closely tied to the judgments we make about ourselves. There are two main ways that comparisons are made. The first is by comparing one's actions to an internal standard that dictates the way one should be and the second method of comparison is that of social comparison, in which one compares oneself to others. This separation or independence achieved by these women seemed to assist them through the process of coping with HIV/AIDS as it allowed them to regain a healthy sense of self-esteem. Through the process of individuation they were able to evaluate themselves according to their own standards as opposed to those of their culture.

Ryan and Deci (2000) developed a self-determination theory which suggests that a core group of innate needs are the basis for self-motivation and personality integration. These needs are the need for competence, the need for relatedness, and the need for autonomy. According to Ryan and Deci (2000) these three needs "appear to be essential for facilitating optimal functioning of the natural propensities for growth and integration, as well as for constructive social development and personal well-being" (p. 68). It is interesting to note that both autonomy and relatedness are mentioned as these seem to mirror the challenge of negotiating independence and dependence that these women faced. This negotiation is also reminiscent of Winnicott's (1958) paradoxical notion that out of the capacity to be alone comes the capacity for relatedness. Through separation and isolation, these women were able to connect to themselves, and this then seems to allow for the ability to authentically relate to others.

For many of these women, surviving their childhoods entailed developing a false self that was invested in hiding a true self that felt vulnerable and dependent. The process of

coping with their HIV status meant that these women were faced with their own vulnerability and need for others in an extreme sense, and the integration of these aspects of themselves into their sense of self was difficult. Although according to Compton (2005) women are more likely to seek social support than men, the acknowledgement of their need for support entailed a significant shift for some of these women.

Speaking about the process of achieving the depressive position, Steiner (1990) comments: "Alongside this comes a shift in preoccupation with the survival of the self to a recognition of dependence on the object and a consequent concern with the state of the object" (p. 46). Many of the women related fantasies about whom they imagined would look after them when they developed AIDS and for many of these women this person was their mother or an aunt. It is interesting to note, though, that although these women knew that they would eventually have to tell their mothers their status, they felt reluctant to do so for fear of causing their mother pain and physical harm. A motivating factor to tell their families for many of the women was the health and well-being of their children. For many of the women acknowledgement of their own vulnerability and dependence on others grew out of a state of concern for their own and their children's survival.

The role of mother in the lives of these women seemed to be a motivating factor in accessing social support, as it also seemed to play an important role in motivating the women to remain alive for their children and this seemed to be a part of the motivation to remain connected to others. Many of the women seemed to have intuitive knowledge regarding links between mind and body, and as the vulnerability of their bodies became increasingly evident as they faced the reality of HIV/AIDS, many of the women began to focus energies on caring for their bodies. Psychoeducation at the clinics they attended around the importance of looking after themselves and reducing their stress levels also prompted many of these women to begin to pay attention to their mental well-being. Cohen, Tyrell and Smith (1991) found that the greater a person's social support network, the less likely they were to become ill. Other studies have found that loneliness is one emotion in particular that can have significant detrimental effects on immune functioning, health and a sense of well-being (Brannon & Feist, 2000). Stress is related to a decrease

in certain cells associated with immune functioning and this effect is greater for people who have less social support and report more feelings of loneliness (Kiecolt-Glaser, Garner, Speicher, Penn, Holiday & Glaser, in Compton, 2005). Many of the women reported knowing that the support they received from those they had disclosed their status to and the support that they felt that they received at the clinics helped them to cope. The benefits of having acknowledged their vulnerability could be seen in that many of the women spoke about reaching a place where they feel the HIV diagnosis improved their lives, as it caused them to review their priorities and invest more energy into their relationships with themselves, their partners and with God. Many of the women also reported feeling that the need to cope with their HIV status had also improved their relationships as they now experienced their spouse or partner as more supportive towards them.

Many of the women related the importance of social support in their lives to a sense of feeling normal again. Spending time with others seemed to be associated with an ability to feel positive emotions again. According to Fredrickson's (1998) 'broaden-and-build' model, positive emotions provide non-specific action tendencies that can lead to adaptive behaviour, such as participating, exploring, helping or taking up challenges. This, in turn, can then lead to thought-action tendencies, which are based on the assumption that when more engaged with the world, one tends to learn more about their environment, others and themselves. This seems to suggest that as the women in the study began to re-invest energy into their social relationships they were able to continue their journey of self-discovery through relationships.

Steiner's (1990) comment regarding the development of an awareness of one's dependence upon others and a subsequent concern for their well-being as a part of the process of achieving the depressive position can also be understood in terms of the shifts made around the care-taking roles that many of the women took on. While initially for many of the women, these roles could have been perceived as attempts to manage anxiety, in that by projecting their own vulnerability into others they were able to maintain the 'strong' role, the integration of their own vulnerability and need for support

allowed many of the women to re-evaluate these roles and look at their relationships in terms of mutuality. For some of the women this constituted painful realizations of feelings of abandonment and unfairness. However, for the most part, many of the women were able to find a balance between their own needs and the needs of others. Many of the women made the decision to not tell their parents their status ever, deciding that their parents would feel too sad and too worried and that their parents might not be able to cope with or survive the news. While this can be seen as an example of a culturally appropriate avoidance goal (Diener, Oshi & Lucas, in Compton, 2005) or as a result of a fear of damaging the object, it is also an acknowledgement of the limits of support that their parents are able to provide. Choosing to keep their status a secret from their parents seems to be for many of the women an attempt to remain connected to a part of themselves that is strong for others, that looks after, that does not disappoint and who is a good daughter. These women were then able to find the necessary support from other relationships. Interestingly, a study conducted by Werner (1995) found that resilient children were the ones able to acknowledge the limits of certain attachments and form other relationships with more healthy attachment figures.

For many, the care-taking roles that they continue to fulfill provide a sense of purpose and belonging. Given the cultural prescriptions for children to take care of their parents, for many of these women the fact that they were able to provide for their parents gave them a sense of pride. A study conducted by Cantor & Sanderson (1999) found that goals valued by one's culture also tended to influence well-being. Cantor and Sanderson (1999) also suggested that one of the reasons that the pursuit of goals contributes to a sense of well-being is because it implies a sense of active participation in life. Having goals has also been linked to a sense of meaning. Being future-oriented or having goals for the future that are realistic and achievable has been linked to higher levels of well-being and life satisfaction. This may be due to the fact that the pursuing and achievement of goals that are meaningful to a person provide a sense of meaning and purpose in life (Compton, 2005).

It is important to note, that for goals to bring a sense of happiness they need to be perceived as having been freely chosen. According to Ryan and Deci (2000) goals that are freely chosen, realistic, valued personally and based on intrinsic motivation tend to bring more happiness and satisfaction than goals that are imposed by others or not valued as highly. This is significant in that for many of the women the fact that they had thought about their care-taking roles and chosen to pursue various forms of them, meant that they had been chosen. Kasser and Ryan (1993) found that goals that were linked to positive relationships and helping others; and that facilitated affiliation, self-acceptance and community involvement tended to enhance a subjective sense of well-being. Many of the women in this study, especially the women who had found a way to help other HIV-positive people, expressed a sense of personal satisfaction with their care-taking role.

The goal of becoming financially independent was also seen as important and many of the women related this to a sense of gaining mastery and independence. However, it was also viewed as an important means of re-engaging with life. This was supported by M's reflection on the difference between her and her sister when it came to starting to cope with an HIV positive diagnosis. While she continued working and interacting with people, her sister chose to withdraw and stay at home, becoming more and more disconnected from life.

Overall, for these women, participation in life took the form of involvement in relationships, especially those that are mutually fulfilling. These relationships fill innate needs (Ryan & Deci, 2000) and seemed to meet the women's needs for social support.
One of the strongest predictors of well-being is the presence of positive relationships in a person's life (Myers, 2000). The need for social interaction between human beings has been shown and cross-culturally, it has been shown that satisfaction with family and friends is linked to higher levels of subjective well-being (Diener et al, in Compton, 2005). According to Compton (2005) there are generally two areas of study associated with positive relationships, namely, social support and emotional intimacy. According to Compton (2005):

Numerous studies…have documented the positive impact that good social support can have on well-being. The perception that one is embedded in supportive social relationships has been related to higher self-esteem, successful coping, better health and fewer psychological problems…Interestingly, one study found that when people sought out social support there were enhanced effects on subjective well-being for positive self-esteem, optimism and perceived control…That is, the impact of the other predictors of subjective well-being was increased if people also had good social support. In a sense, good social support helped to create a rising tide that increased the effects of all the other predictors (p. 52).

Whereas research has shown the positive effects of good social support, it has shown even greater effects on levels of happiness and well-being when these relationships are intimate. According to Cummins (1996) intimate relationships with one's spouse, family and close friends are the strongest predictor of a high level of life satisfaction. Committed relationships have also been found to be a source of personal growth, in that the difficulties inevitably experienced in any relationship can be harnessed as motivation for self-exploration and gaining a deeper understanding of the self and one's partner. According to Tashiro, Frazier, Humbert and Smith (2001) difficulties in a relationship can create the need for partners to explore their own expectations and needs and the impact of their unconscious issues on the relationship. If successful in coping with the difficulties, both partners increase their development and the maturity of their relationship. This is supported by the fact that in the initial stages of coping many of the women reported going through a stage of feeling that they did not want an intimate relationship. The reasons for this ranged from a fear of being rejected to fearing that the new partner would not treat their children well. However, for the women that had moved from this stage toward an engaging with their needs for intimacy, it seemed to indicate a shift toward a more integrated view of themselves i.e. the fact they are HIV-positive does not make them unlovable.

Overall though, these women's struggle to negotiate the tension between their dependency needs and their need for independence seemed to result in relationships that were more considered and a relationship with themselves that was more tolerant and nurturing. Their needs for self-reliance were balanced with their need for support from others and their need to be a care-taker was balanced with a need for caring from others. Ultimately, their ability to re-engage with relationships and once again actively pursue goals and participate in life seems to signal a maturity of the personality that Freud (1920) related as the ability to work and to love. Their need to give back to the community through helping other HIV-positive people seems to be related to Jung's (1933) idea of needing to give back to humankind during the second stage of his individuation process. He related this to the acts of raising children and contributing through work and relationships to the growth of collective consciousness.

The fact that these women were able to re-engage with life suggests a future outlook and experiencing life as having a sense of meaning. Associated with this future outlook for many of these women was a sense of optimism and hope. Optimism is associated with the tendency to look at the future with hope and positive expectations (Compton, 2005) and has been associated with higher levels of happiness and life satisfaction (Diener et al, in Compton, 2005). Optimism regarding the way that one perceives the status of one's physical health has also been linked to experiencing fewer health problems (Scheier & Carver, 1992).

According to Compton (2005) people who have high levels of hope tend to experience more positive emotions. In addition to this, high levels of hope have also been associated with the anticipation of greater well-being in the future, higher levels of confidence, more success when dealing with stress, more flexibility in goal-planning and higher levels of social support (Snyder, Rand & Sigmon, 2002). Kubler-Ross (1970) also emphasizes the role of hope in the resolution of grieving:

> The one thing that usually persists through all these stages is hope…in listening to our terminally ill patients we were always impressed that even the most accepting, the most realistic patients left the possibility open for some cure, for the discovery of a new drug or the 'last minute success in the research project'…it is this glimpse of hope which maintains them through the days, weeks, or months of suffering (p. 122 - 123).

This hope manifested in these women's lives in a variety of ways. For some it manifested as a hope that meaning would emerge from their experience. For others it was the faith they maintained in the belief that God would protect them and their children. For others it was the ever-present wish that a cure would be discovered. Kubler-Ross (1970) explains the importance of hope in her statement that the patients who stopped hoping usually died within 24 hours of having given it up.

While the hope for a cure could be said to be unrealistic, Taylor and Brown (1988) found that overly optimistic and exaggerated evaluations and beliefs about the self, the future and perceptions of control were all positively correlated with mental health. Taylor, Kemeny, Reed, Bower and Gruenwald (2000) found that these positive illusions were associated with more effective coping with adversity and positive physical health outcomes.

It is also significant that the majority of the women interviewed were found to have a ready sense of humour. According to Compton (2005): "people who score high on a sense of humour scale also tend to score high on measures of optimism, extroversion, and capacity for intimacy and scored low on neuroticism. High scorers also showed less negative self-esteem and tended to use better coping strategies to deal with stress" (p. 115). According to Lefcourt (2002) the overall effect of humour is that it enables people to better cope with stressful situations, to recover more swiftly from illness or injury, to deal more effectively with anxieties about dying, to cope with pain more easily, and

lastly, humour has been found to have significant effects on immune functioning.

Another of the processes associated with Jung's process of individuation is that of reconnecting to God. Jung (1933) regards religion of any sort to be the fulfilling of an innate 'religious function'. Although no opinion was written about by Jung (1933), his theories on religion and life after death imply that he may have considered death to be merely another transition, rebirth or individuation (Battista, 1979). According to Compton (2005) there are a variety of studies that suggest that higher levels of religious faith, regular attendance at religious services and regarding religion as important in life correlate with higher levels of well-being. This could be due to a number of reasons, such as: religion providing a sense of meaning and purpose in life; greater levels of social support from the religious community; and increased self-esteem through self-verification. For these women, their sense of faith in God seemed to provide both a sense of protection and social support from the church. Jung (1933) associated this experience of connecting to a belief in something bigger than oneself to be an important part of the individuation process as it implies a preparing for death as well as a connection to a greater collective sense of the Self.

Jung (1933) describes how it is the task of the second half of life to find meaning and share wisdom. For many of the participants in this study, finding a sense of meaning in their HIV-positive status was also an important part of the process of coping. For most of the women, the sense of having survived the process of coping was a source of much meaning in that they now felt stronger as individuals. Some even reported a sense of having been saved by HIV, explaining that it encouraged them to find a new self-awareness and new ways of being in the world. Many felt that their HIV-positive diagnosis had allowed them to really appreciate certain relationships in their lives and find meaning in them. This ability to find meaning is associated with emotional intelligence, which is also associated with self-insight or the ability to understand one's own emotional life; good social skills, which include empathy and insight into the emotional life of others; and self-control or the ability to regulate one's own feelings and impulses towards the achievement of goals (Mayer, Caruso & Salovey, 2000). Averill

(2002) proposed that people who are able to use their emotions in creative ways are able to create more meaning and connectedness in their lives.

Battista (1979) comments on the difficulties associated with the last stage of Jung's (1933) stage of individuation:

> Initially, the hero or heroine may be tested by a number of trials. Although individuals may first be called upon to prove their courage by slaying various beasts and performing difficult tasks, eventually they are called to submit themselves to that which is greater than they are, the Self. The most frequent difficulties involve the ego's attempt to possess the Self and thus maintain its control. This result is an inflation or aggrandizement of the ego… Instead, the individual must submit to the Self, to be contained by it, and thus transformed… (p. 120).

The process of submitting to the Self, being contained by it and being thus transformed, in the cases of these women, seems to refer to the acceptance of self that they seem to achieve once the various difficult aspects of their emotional experience has been confronted, which is captured by Jung's description of his process of individuation. This move toward a greater sense of wholeness and integration allows for an embracing of strength and vulnerability, dependence and independence, joy and sadness, loss and gain. Mudd (1990) speaks about facing death as a challenge "to surrender to inevitable fate and embrace the dark self in order to gain true selfhood. It exhorts us, long before actual physical death, to undergo a process that will release the ego from the slavery of the self-preservational instinct into a far fuller life" (p. 126). Yalom (1996) refers to this as a "heightened existential awareness" (p. 7), which is gained through facing mortality. This awareness incorporates a "new appreciation for the preciousness of life" (Yalom, 1996, p. 7).

These women's capacities for strength that they, in their own words, attributed to having survived previous hardship, is supported by a study done by Campbell-Sills (in Arehart – Treichel, 2005). This study found that individuals endorsing high levels of childhood neglect with low levels of resilience manifested high levels of psychiatric symptoms, and that individuals with high levels of childhood neglect and high levels of resilience manifested low levels of psychiatric symptoms. Most interestingly though, they found that individuals with high levels of childhood neglect and high resilience reported fewer psychiatric symptoms than those reporting low levels of childhood neglect and scoring high on resilience. According to Campbell-Sills (in Arehart –Treichel, 2005):

> …the finding is consistent with [the] contention that resilience constitutes not just recovery but growth and strengthening from adversity. Individuals who suffered from adversity in their home environments yet coped effectively may have experienced additional personal growth beyond that which characterized the young adults who came from more nurturing environments. The result also may be explained in the context of stress-inoculation theory, where a psychological and physiological 'toughening' occurs through exposure to moderate levels of stress (p. 14).

This strengthening of the ego through surviving previous hardship could be likened to Mudd's (1990) suggestion that Jung's transcendent function is built upon the experience of having lived through the threat of physical death, and is "nothing short of the ego's achieved capacity to die repeatedly an ongoing series of conscious voluntary deaths in the service of individuation" (p. 127).

Ironically, this psychological 'toughening' associated with resilience seems to involve a greater awareness of vulnerability and for the women in this study, this integration of the opposing aspects of themselves seems to allow a freedom of expression and an openness to experience, which allows for connection to themselves, others and for an ability to participate in life fully. Thus, coping with HIV/AIDS seems to entail a rebirth in that

beneath the wings of Aidos (Goddess of Shame), these women confront their shame and find a self that they can be proud of.

The move toward the depressive position (Klein, 1946; Winnicott, 1954) entails a greater degree of integration and an increasing ability to tolerate ambivalent feelings toward the object. Hence, Jung's resolution of the individuation process, which is the knowledge that we are separate and alone and yet connected to all that is – the greater collective – seems to represent the ultimate depressive position – the capacity to tolerate ambivalence towards life itself. The human relationship to life seems to represent the ultimate ambivalence in that we know it is to end and we hate life for this, because we love life.

7.3. CONCLUSION

This section attempted to integrate the themes that emerged from the interviews with the women who participated in this study. It also attempted to combine three theories, namely analytical psychology, object relations theory and positive psychology, and integrate them into the themes that emerged in order to create an in-depth understanding of these women's experiences of coping with an HIV/AIDS in a way that was culturally sensitive. The interplay between disconnection and reconnection was interpreted as reaction to loss and a part of the process of mourning. This was then linked to the process of individuation as related to the development of the self and a movement toward the depressive position and greater independence and paradoxically, a greater capacity for relatedness to themselves, others and life itself.

CHAPTER EIGHT

CONCLUSIONS AND RECOMMENDATIONS

Death belongs to life as birth does.
The walk is in the raising of the foot as in the laying of it down.

Rabindrath Tagore

8.1. INTRODUCTION

This chapter presents the broad conclusions that can be drawn from this study. A brief discussion on the limitations of the study is provided in addition to avenues for further study. A few recommendations are also made with regards to the mental health treatment of HIV-positive women.

8.2. CONCLUSIONS DRAWN FROM THIS STUDY

- Coping is a process of disconnection and reconnection

The findings of this study suggest that coping is not static, but rather a shifting process that entails an acceptance of the fact that there will be times of not coping and times of coping. It also emerged that this process entails disconnection and reconnection, which was evident in these women's descriptions of the re-negotiation of closeness or distance from their own emotional experience and in all their relationships. An urge to disconnect in order to protect themselves from loss was described, as was an urge to re-connect in order to feel comfort, love, acceptance, belonging, a sense of being 'a part of', and a sense of being alive. This process of disconnection and reconnection was also evident in these women's attempts to renegotiate their dependency needs with their need for a sense of self-sufficiency and independence and was interpreted in this study as being a part of the process of individuation or moving toward a greater sense of integration or wholeness.

- Coping entails the ability to know one's own experience

As mentioned previously in this study, Bion (1962) saw the primary struggle of life as being the tension between having the desire to know and understand the truth about one's own experience, but also experiencing a fear or aversion to that knowing and understanding on the other. The success of this quest for knowledge about the truth of

one's experience is found in the capacity to actually have the experience, in the sense of really going through it and suffering it, rather than seeking to avoid or dismiss it. While it was evident in this study that defenses are employed initially to mediate the overwhelming emotional experiences associated with receiving an HIV-positive diagnosis, an integral aspect of these women's descriptions of coping included a sense of being able to open themselves to their emotional reactions. This is necessary for the process of mourning and for the process of self-discovery that individuation, which is associated with the development of the self, entails. Both these processes seem to be important for coping.

- Coping is mourning loss effectively

HIV/AIDS entails a number of losses in a variety of spheres of life, such as, partners, family members, children, financial stability, the ability to feel happy, a previous sense of self, etc. What emerged from this study is that in order to recover from these losses and traumas and in order to re-engage with themselves and others, to once again participate in life and find meaning in their suffering, the process of mourning needs to occur. While resolution of mourning is unique to each individual and tends to be an abstract concept, in that mourning is a process that can continue for years with losses re-evoking previous experiences of loss with an end to the process that is unclear, what emerged from the study as important is that acknowledgement of loss occurs so that necessary adaptations for continuing can be made. Hence, the resilience observed in these women seems to be the ability to mourn effectively and once again re-invest energy into life.

- Coping is acceptance and integration

While many of the women in this study referred to 'just having to accept' their status, which could be construed as an attempt to evade the real emotional implications of this, the interviews revealed a significant period of pain and suffering before this acceptance, where these women confronted the losses, vulnerability, shame and anxiety resulting from HIV-infection. For many of them the confrontation with death implied by a

diagnosis with an incurable illness was both physical and psychological. Serious illness caused many of the women to face their physical vulnerability and through this their emotional pain. Coping with the loss, shame and vulnerability entailed a change in their view of themselves, their relationships and their sense of purpose. The integration of their more vulnerable parts enabled them to re-connect with aspects of the self that were stronger and more able to experience life fully. They described being able to feel normal and happy again. Fredrickson's (1998) broaden and build model suggests that the broadening of awareness that positive emotions encourage, allows for learning and the building of future emotional and intellectual resources. Hence, thriving was seen, in that these women, through their confrontation with the difficulties, managed to emerge stronger, more integrated and better equipped to deal with further losses.

- Coping can be understood through theoretical integration

Lastly, an indirect aim of the study was to integrate three theoretical approaches, namely positive psychology, object relations and analytical psychology. This was achieved through using Jung's theory of individuation and Campbell's (1972) interpretation of it, namely The Hero's Journey, as an overarching frame for the theoretical discussion. Within this frame, Kubler-Ross' (1970) stages of mourning were integrated with relevant object relations concepts. The initial separation that occurred after diagnosis from themselves and others and the gradual reconnection to themselves, others and life was discussed in relation to Jung's (1933) description of confronting the persona, shadow, animus and Self, Kubler-Ross' (1970) initial stages of mourning, Winnicott's (1960b) description of separation and the role it plays in the move from dependence to independence, Winnicott's (1958) capacity to be alone, Klein's (1935) description of the move from the paranoid-schizoid to the depressive position and Bion's (1959) quest to fully know one's experience. A number of concepts from positive psychology were also found to be relevant to these women's experience of coping, such as: coping styles, social support, participation in life, positive goals, autonomy and resilience. Jung's theory was the glue that integrated these approaches into a sense of theoretical coherence and the core of Jung's theory, which is always the integration of both polarities, allowed for

space to explore both distress and coping, both of which are entailed in the process of coping. The use of analytical psychology, object relations theory and positive psychology seemed to allow for a more holistic approach to understanding these women's experiences.

8.3. LIMITATIONS OF THE STUDY

- The first limitation of this study is the small number of participants used. However, while a greater number of participants may have yielded more categories, the fact that categories did begin to repeat after 10 interviews, suggests that the number of interviews would most likely have needed to be exponentially greater in order to yield fewer and fewer categories. Lastly, it is important to bear in mind that this study aimed to create an in-depth understanding of these women's experiences and is not meant for generalization to a greater population.

- The fact that these women were recruited from an urban hospital may have influenced the findings of the study regarding sense of self. The fact that these women live in an urban area may have contributed to the sense that these women straddle two cultures – a traditional African culture and a more Western urban culture. While interviews with rural women may have yielded a very different set of findings, it is thought that the fact that many rural people move to the city specifically in order to gain better access to treatment for HIV/AIDS, that a study in an urban setting was appropriate.

- The fact that only women who could speak English or Afrikaans were interviewed may also have skewed the results slightly, in that women who are unable to speak English or Afrikaans living in the city may have had different experiences with regards to access to treatment and the need for assistance from others in order to survive.

- The fact that participation in the study was on a voluntary basis may have affected the results found in this study in that women who are coping with their status but chose not to participate may have yielded a different set of personality dynamics, especially with regards to the category regarding coping as being able to talk about your status. However, the fact that this theme repeated throughout all the interviews and that the women who agreed to participate expressed a desire to help others through their participation, it is likely that this theme is indeed an integral part of the process of coping.

- Lastly, the fact that this study focused on recruiting participants who felt that they were coping may have influenced the results, in that as the study revealed, coping is a process, and women who felt that they were not coping and were therefore excluded from the study, may have provided valuable information on the initial stages of the process where not coping is an integral part of the experience.

8.4. RECOMMENDATIONS

8.4.1. Recommendations for the mental health treatment of HIV positive women

- Coping is a process and it vital for those intervening to respect this. Attempts to assist these women to cope prematurely may lead to them missing essential experiences related to aspects of themselves that are painful to confront, but essential to experience and integrate. Winnicott's (1958) notion that the true self can only evolve in the presence of an unobtrusive other who will not interrupt the continuity of its experience of itself is relevant in this regard. What seems to be called for in the initial stages of coping is a therapist who can effectively mirror and hold the individual's experience of themselves.

- In the initial stages of coping, primitive defences are likely to be employed and it is important to be able to recognise the use of healthy or normal splitting and

projection. Excessive or extended use of these defences may call for a greater degree of intervention, but for the most part what is required from the therapist seems to be an ability to be present and the ability to contain the patient's overwhelming emotional experiences, but also their own reactions to the overwhelming emotions and at times, frightening experiences of the world that these women report. According to Winnicott's (1958) theory, the self can develop when the holding environment (provided by the therapist) does not unnecessarily impinge on the other. In other words, in order for the therapist to avoid 'substituting her own impulses' in the therapy situation, it is necessary for her to maintain or restore her own sense of well-being before she can act as a tension regulator for the patient.

- It is also important to recognise that coping seems to be a process of mourning and that this seems to entail a number of stages. Although the experiences of most of the women seemed to conform to these stages, there was a sense that each women's experience of them and progression through them was unique. In this regard the therapist needs to be aware of differences in experience that occur and of the influence of previous losses on an individual's capacity to mourn. According to psychoanalytic attachment theorists the degree of attunement that the mother achieves in the mother-child relationship contributes to the development of symbolic thought in the infant (Fonagy, 2004). In other words, the ability of the therapist to match her patient's progression through the stages of mourning may contribute to the effectiveness of the therapy to assist the patient to 'think' about and find meaning in their experience.

- This study revealed that the process of coping with HIV/AIDS entails a number of significant shifts in identity, relationships with others, relationship with God, and ultimately with life itself. The magnitude of these shifts needs to be recognised by intervening health professionals. Winnicott (1960) referred to the analytic relationship as a transitional space. According to Knight (2004) this "transitional area of human experience is a specific developmental phase of 'intermediate

experience', neither fantasy not reality but illusion, a blend of both spheres" (p. 88). Using Winnicott's idea of therapy as transitional space, Summers (2000) suggests that the therapist's task is to provide sufficient space in the therapeutic relationship:

> There is no illusion here of a blank screen, but the analyst's
> role includes the provision of a certain 'formlessness' in the
> setting. That is, the analyst's task is to be flexible enough to
> adapt to the experience the patient needs to create. Too much
> form or structure restricts the space the patient can make use
> of in order to realize the yet unborn self (p. 92)

This realization of the yet 'unborn self' is reminiscent of Jung's (1933) concept of rebirth. Summers (2000) states that the aim of psychoanalytic therapy is to facilitate potential ways of being that relate to authentic experience and that the therapist's task is to find the 'not yet fully developed' self beneath the surface of social adaptation. Thus it appears that the discovery of the true self (Winnicott, 1960) or authentic self, or of Jung's (1933) Self entails a process of confronting defensive ways of being in the world, i.e. Jung's (1933) persona or Winnicott's (1960) false self, and integrating the aspects of the self that have been relegated to the shadow or split off in order to achieve a greater sense of wholeness or integration and the ability to relate authentically.

- It is important to recognize that themes around dependency versus independence seem to play a vital role in this process of coping and it is likely that these might play out in a therapeutic relationship. The ability of the therapist to recognize and understand the processes behind this negotiation of needs would most likely assist HIV-positive women to find their own resolutions.

- The experience of shame as a result of the stigma surrounding HIV/AIDS was evident in this study and seemed to play a fairly significant role in the

participants' changing sense of self. It also emerged as one of the most painful experiences for the women in the study to manage and the need to defend strongly against the experience of shame emerged. Studies have explored the relationship of non-disclosure to shame in psychotherapy (Hook & Andrews, 2005; Macdonald & Morley, 2001). Both studies found strong support for the relationship between non-disclosure and shame in psychotherapy. In other words, shameful experiences tend to be avoided by patients in therapy as there is a tendency to either judge aspects of themselves as unacceptable or have expectations that others (the therapists) would blame or judge them. Hence, sensitivity in this regard is required. This study found that being able to talk about their HIV-positive status was regarded by the participants as an important part of the coping process, which suggests that patients should be encouraged to talk about their status and the shameful feelings related to it, however, it should be held in mind that these individuals are especially sensitive to any judgment that they may perceive is being made about them. Hook and Andrews (2005) found that non-disclosure of shameful feelings was related to depression-related symptoms and behaviour and that the results indicated that the disclosure of shame-related issues demonstrated a positive response in the recovery of depressive symptomatology. This finding supports the findings of this study and highlights the importance of identifying patients' shame and using empathy and validation to manage shame.

- Lastly, it appears that the role of the therapist is a dual one, which seems to entail preparing the patient for death and simultaneously preparing them to continue living. Winnicott's (1958) theory around the development of the capacity to be alone and the associated development of the capacity for relatedness is useful in this regard. According to Fonagy (2001) Winnicott's capacity to be alone is developed through three qualities of the holding environment, namely: that it allows for safety when experiencing the internal world, that it understands that ego-relatedness develops slowly through gradual exposure to external events, and that the holding environment allows for the opportunity to generate spontaneous

creative gestures and that the goalorientedness of the individual is acknowledged. Winnicott (1958) believed that if the holding environment could provide these qualities then "…concerns with mind and meaning can override his preoccupation with his physical needs" (p. 99). Translated into therapy, if the therapist is patient and able to create enough space for the individual to explore their inner worlds with safety and freedom of expression, the individual can internalize a good enough object that allows for the ability to be alone and the ability to relate fully to others and find meaning in experience.   Mudd (1990) also speaks about the analytic space and states that "the analyst's fundamental task then is to keep the patient 'alive' while simultaneously helping the patient to learn how to die…herein lies the possibility of the emergence of the transcendent function and with it the hope of personal authenticity" (p. 138).

8.4.2. Recommendations for further research

While this study attempted an initial in-depth exploration of African women's experiences of coping with HIV/AIDS, further understanding is required in a number of areas:

- This study found that the role of gender is a significant factor in the process of coping with HIV, hence exploration into the experiences of HIV-positive men is recommended.

- This study examined the process of coping from the perspective of women who feel that they are coping. This study included a number of women who have lived with HIV for a long time, some in excess of 15 years. As revealed by this study, time to fully process the experience and the implications of HIV for their lives is important in the process of coping. Therefore, an exploration of the experiences of women who are not coping or who have more recently discovered their HIV

positive status may reveal important information with regards to obstacles to coping that occur within the process.

- Further research on the experiences of children with HIV-positive parents is recommended. This study revealed that coping with HIV/AIDS is a process of mourning that entails stages of not coping, which may impair parents' abilities to be emotionally available to their children. An exploration of these children's experiences may provide significant information with regards to the impact of a parent's emotional struggle on the development of the child.

- Lastly, further research is recommended with regards to the experiences of HIV-positive children. This study revealed that an HIV-positive diagnosis entails a shift into later stages of individuation or development and while these women were found to eventually cope with this, children, due to incomplete development, will most likely have an entirely different experience.

8.5. CONCLUSION

Although limited in scope, this study aimed to present a theoretically integrated understanding of the subjective psychological experience of women positively living with and dying of HIV/AIDS with the aim of identifying the significant cognitive, emotional and social themes involved in their subjective sense of coping. Further study in this area is recommended due to growing numbers of HIV infections and transmissions and the implications of this for the future mental health of our population.

The living spirit grows and even outgrows its earlier forms of expression; it freely chooses the men in whom it lives and who proclaim it. The living spirit is eternally renewed and pursues its goal in manifold and inconceivable ways throughout the history of mankind. Measured against it, the names and forms which men have given it mean little enough; they are only the changing leaves and the blossoms on the stem of the eternal tree.

C.G. Jung – Modern man in search of a soul

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