



# *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 Strümpfer, 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 21<sup>st</sup> 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 & Sibiyi, 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 (25<sup>th</sup> percentile) lost CD4 cells at a rate 1.55 times faster than those high on optimism (75<sup>th</sup> 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.



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## ***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 Bantu; 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 18<sup>th</sup> 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 can 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.