

AN EXISTENTIAL PERSPECTIVE ON
A WOMAN'S SEARCH FOR MEANINGFULNESS
WHILE LIVING WITH HIV/AIDS

BY

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ABSTRACT

Key words/concepts: HIV/AIDS, existentialism, meaningfulness, existential vacuum, non-being, higher being, context, gender, culture, case study.

This mini-dissertation examines how an African woman – as an individual – makes meaning of her life amidst her HIV positive status. Her search for meaning was explored through semi-structured interviews. The case study is situated within a South African context where HIV/AIDS has become a pandemic. The methodology used in this research is explorative and qualitative in nature, thus facilitating a process of interpretation resulting in thick description drawing on existential concepts. Relevant information from the participant's counselling therapeutic process, prior to the research, is incorporated in the thick description of her living with and making meaning of HIV/AIDS.

An Existential perspective on the participant's psychological experiences concerning meaningfulness and being is discussed in terms of themes drawn on in semi-structured interviews. Special emphasis is also placed on the concept of an "existential vacuum" that an individual might experience when affected by something as life changing as HIV/AIDS. Notions of anxiety and non-being are also key concepts in this particular case study. Spirituality and the sense of a Higher Being are explored as fundamental in the domain of this individual's life, and therefore also in her production of meaning, as well as self-contemplation.

A constructionist epistemological approach is taken according to which the aims of the research are examined and interpreted. Attention is given to the participant's experiences of the impact of both African and Western worldviews on her sense of being within the South-African context. Her perceptions and beliefs, as a Tswana woman, concerning traditional customs and significant figures are discussed, for example: sangomas, witchdoctors, ancestors, forefathers, HIV/AIDS, etc. These, often opposing, points of view are explored in detail when the biological,

psychosocial, cultural and political contexts are taken into account. These are, in turn, coupled with an analysis of gender relations and their associated power relations within societal structures. Further examination reveals the expected physical and psychological phases associated with the HIV/AIDS disease.

The woman used in this case study relays her thoughts and experiences directly to the researcher and reader, as transcripts of semi-structured interviews with her are used in the text. Ethical considerations pertaining to both the participant and the researcher are also conveyed exhaustively. Issues in the interviews that are touched upon, include: How multiculturalism is perceived and experienced, the effects of stigmatisation, self-awareness and the conscience, traditional rituals and values associated with HIV/AIDS, transcendence and the responsibility for a sense of self. Arrays of emotions that are experienced under the circumstances include anger, depression, despair, defiance, hope and alienation. There is also a strong focus on the interaction between people, and especially on what is deemed as “meaningful relationships”.

OPSOMMING

Sleutelwoorde/-konsepte: MIV/VIGS, eksistensialisme, sinsrykheid, eksistensiële vakuum, konteks, spiritualiteit, nie-bestaan, geslag, kultuur, gevallestudie.

Hierdie mini-tesis handel oor hoe 'n Afrika vrou – as 'n individu – sin maak van haar lewe te midde van haar MIV positiewe status. Die gevallestudie vind plaas binne die Suid Afrikaanse konteks waar MIV/VIGS 'n pandemiese realiteit is. Die metodologie wat gebruik word is eksplorerend en kwalitatief van aard, wat ruimte laat vir 'n interpretatiewe “dik beskrywing” van die deelnemer se belewenis van haar werklikheid. Temas is afkomstig van die semi-gestruktureerde onderhoude wat met die deelnemer gevoer is. Die deelnemer het 'n proses van terapie ondergaan, voor die navorsing 'n aanvang geneem het, en relevante inligting daaruit is aangewend vir 'n “dikker beskrywing” van haar belewenisse van om te leef met en sin te maak uit MIV/VIGS.

Eksistensiële perspektiewe op die deelnemer se psigologiese belewenisse van sinloosheid asook die vorming van sinvolheid, word deeglik bespreek. Haar belewenis van 'n “eksistensiële vakuum” word beklemtoon. Hierdie vakuum kan ontstaan wanneer 'n individu geaffekteer word deur die lewensimpakterende werklikheid van MIV/VIGS. Belewenisse soos angste en nie-bestaan is ook fundamenteel in hierdie gevallestudie. Spiritualiteit en die bewus wees van 'n Hoër Entiteit vorm 'n belangrike deel van die deelnemer se soeke na en konstruksie van sin binne die multi-kontekstuele realiteit waarbinne sy haarself bevind.

Die navorsing word vanuit 'n konstruksionistiese epistemologie benader. Aandag word ook geskenk aan die deelnemer, wat van Tswana afkoms is, se persepsies en belewenisse van tradisionele figure en gebruike soos byvoorbeeld sangomas, toordokters, voorgeslagte, MIV/VIGS, ens. Haar hantering van beide Afrika en Westerse invloede op haar sinsbelewenis binne die Suid-Afrikaanse samelewing word bespreek. Hierdie gewaarwordinge word gevolglik

gekombineer met 'n analise van geslagsverhoudinge en hulle geassosieerde magsverhoudinge binne sosiale strukture. Die relevante gepaardgaande fisiologiese en psigologiese aspekte rakende MIV/VIGS word ondersoek.

Die vrou waarop die gevallestudie geskoei is, verbaliseer haar gevoelens en belewenisse direk aan die navorser en leser. Dit word gedoen deur middel van direkte aanhalings wat verkry is gedurende die voer van semi-gestruktureerde onderhoude. Etiese oorwegings wat van toepassing is op die deelnemer en die navorser word ook breedvoerig uiteengesit. Onderwerpe wat tydens onderhoude aangeraak word, sluit in: Hoe multi-kultureelheid begryp en aanvaar word, die gevolge van stigmatisasie, selfbewustheid en die gewete, tradisionele rituele en waardes wat bydra tot MIV/VIGS, transendensie en verantwoordelikheid vir 'n sin van die self. 'n Spektrum van emosies, soos depressie, angs, onsekerheid, woede, moedeloosheid, hoop en verwerping, word ook bespreek. Klem word geplaas op die interaksie tussen mense, veral met betrekking tot sinvolle relasies.

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DECLARATION

I declare that: *A woman's search for meaningfulness while living with HIV/AIDS*, is my own work, that all the sources used or quoted have been indicated and acknowledged by means of complete references, and that this mini-dissertation or research project was not previously submitted by me for a degree at another university.

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...

Notes about the text:

1. The participant in this research granted permission to take part in this study.
2. Names have been changed to protect the identity of the participant.
3. The feminine third person pronoun has been used throughout in order to simplify the reading.

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CHAPTER 1: INTRODUCTION

1.1. Motivation for research

1.1.1. *Research rationale*

According to statistics (UNAIDS, 2004), 37 million (range: 34.6-42.3 million) people worldwide are infected with HIV/AIDS, of which 25 million (range: 23.1-27.9 million) reside in sub-Saharan Africa. With a total of 5.3 million (range: 4.5-6.2 million) infected people, South Africa has the largest number of people living with HIV/AIDS in the world (UNAIDS, 2004). Worldwide, 20 million people have already died of HIV/AIDS since the disease has been identified in 1981. HIV/AIDS is the world's fastest-growing epidemic and no vaccine has yet been invented to cure the disease (Harrison, Smit & Meyer, 2000).

It seems that 55% of infected adults are women (UNAIDS, 2004). Adolescent girls and young females are six times more likely than males to be infected with HIV/AIDS. Women between the ages of 15 and 30 are the worst affected groups in South Africa (Squire, 1993). Political, cultural and economic concerns combined with historically powerful patterns of gender discrimination and the neglect of female sexuality, may be part of the interconnectedness of contaminated systems that impact destructively on infected individuals. In addition, biology makes females automatically and physiologically much more vulnerable to contract HIV/AIDS (Evian, 2000).

It follows that South Africa is facing a crisis of enormous proportions where the challenges associated with HIV/AIDS are enormous and exceed the medical diagnoses and treatment of the disease (Evans, 2002). Multiple losses of lives will occur in brief periods of time, resulting in far reaching psychological and other consequences for individuals who are HIV positive as well as for their significant others (Dansky, 1994). As a result of so much loss of lives, strategists in the fields of health care, industry, commerce and other important areas, are projecting foreboding scenarios that have potentially calamitous consequences for this country.

As more HIV infections develop into AIDS cases, the epidemic, with its social and economical consequences, is becoming increasingly visible (Whiteside & Sunter, 2000).

On the human and personal level, the amount of suffering will be vast as individuals infected by HIV/AIDS may be brought face-to-face with issues that include the loss of health, income uncertainties, spiritual quests and uncertainty about relationships with significant others. Individuals infected with the HIV virus frequently experience an existential vacuum and sense of meaninglessness, due to the impact of the disease on all levels of their existence. Psychological experiences of fear, loss, grief, guilt, denial, anger and anxiety may result in feelings of meaninglessness (Van Dyk, 2005). Fabry (1968) contends that this sense of meaninglessness often results in an existential vacuum, leaving many individuals feeling alone, unprotected, drifting and in despair. Research has drawn attention to the frequency of attempted and completed suicides, as well as suicidal tendencies and thoughts (Van Dyk, 2005).

Ecological systems surrounding the participant form patterns of interrelatedness in the context in which the individual exists (Becvar & Becvar, 2000). The uncertain prognosis and course of the HIV-illness, as well as the threat of death from AIDS related opportunistic diseases; contribute to the experiences of helplessness and concern about the future. It also significantly impacts on the psychological and social realities of the individual who is infected by the virus. Disclosure or the lack thereof, brings a sense of apprehension, as it may affect relationships with the spouse, family, or both. Concern about children also contributes towards extreme psychological discomfort. There are issues of stigmatisation, leading to the isolation of the infected person and a resultant lack of social and emotional support (Tegius & Ahmed, 1992).

1.1.2. Research problem

The participant is a woman of Tswana origin, who is 41 years of age and was born and brought up in Kimberley. She is the youngest of five children. Two of her brothers as well as a sister

have already passed away. The participant's father died in 1996 and her mother passed away during 2003. She is divorced from her first husband and they have a daughter who is currently 21 years old.

The participant has been married to her second husband since 1999. He was diagnosed with AIDS during 2004 and died at the end of 2004. Although her husband had pre-knowledge of his diagnosis, his HIV status was only disclosed to her a few months before he died. They were sexually involved while he was living with AIDS. The participant went for an HIV test in December 2004 and was consequently diagnosed as being infected with HIV.

The participant is working as a nurse at the Hillbrow Hospital in Johannesburg and recently graduated as a staff nurse. She and her daughter live together in a house in Hillbrow and make use of English as their home language.

The researcher met the participant at a workshop that the researcher presented for the Department of Health at ICAG (Institute for Child and Adult Guidance), University of Johannesburg, during February 2005. Thereafter, the participant decided to come for therapy.

She is experiencing difficulties in coping with the losses of significant others in her life, accepting her own HIV status, living with HIV/AIDS, disclosing her status to her child and family, stigmatising issues, spiritual quests, and concerns about her profession and income. The participant's experience is that of an existential vacuum as she expressed a sense of frustration of the will to meaning, emptiness, aimlessness and void together with fluctuating suicidal ideation. She is therefore desperately in search of meaningfulness and expressed the need to discover ways to live with HIV/AIDS, her suffering and to face death, something that seems threatening and inevitable to her. A process of psychotherapy emerged in which the researcher and the participant searched for the value of meaning and explored the participant's options for creating a meaningful existence whilst becoming the architect of her life.

During psychotherapy the participant and the researcher discussed the possibility, need and benefits of doing research on the phenomenon of a woman who is HIV positive, is experiencing an existential vacuum, and who is in search of meaningfulness in her life. The participant feels convinced that she will benefit from entering a process of exploring her progress on her journey and thereby offer other individuals the opportunity to share her existential experiences of broken reality. She therefore volunteered to participate in the research. The participant values the relevance and significance of existential perspectives that the therapist presented to her and feels that the principles of existentialism usefully conceptualise her experiences of being HIV positive and its impact on her whole existence. She experiences a sense of universality with the suffering and the search of meaningfulness by existentialists like Victor Frankl and Rollo May, as interpreted and presented to her by the therapist. In Frankl and May's conceptualisations of suffering, experiences of an existential vacuum and the search for meaningfulness, the participant found verbalisations of experiences in circumstances, that created a space for her in which she could construct meaning within her existential reality.

She also expressed a need to communicate the outcome of the research to other individuals who might have similar kinds of experiences, in order for them to share in her unique creation of meaningfulness. This might possibly contribute to their search for meaningfulness while walking their individual journeys. Psychotherapy will be continued as long as the participant experiences and expresses the need for it.

1.2. Aims and objectives of research

1.2.1. Research aims

This research plans to explore and describe a woman's search for meaningfulness while being HIV positive, and to relate these findings to key propositions of existentialism, imbedded in the rich context within which she lives.

1.2.2. Object of study

An in-depth analysis of a single individual case will be the object of investigation and unit of analysis.

1.2.3. Type of study

The aim of the research is mainly *exploratory* because it employs an open, flexible and inductive approach to research as an attempt to look for new insights into phenomena in order to formulate rich descriptions (detailed) of the phenomena (Durrheim & Wassenaar, 2004). The research also aims to be naturalistic (Denzin & Lincoln, 2000), holistic and inductive for it is studying phenomena as they unfold in real-world situations as interrelated wholes by using an inductive approach. According to Creswell (1998), an inductive approach is adopted in order to make a series of particular observations, and it attempts to patch these together to form more general but speculative suggestions.

The purpose of these research findings is *applied* and has a practical application in contrast with findings derived from basic research, which is typically used to advance fundamental knowledge of the social world. Kevin Durrheim, refers to Butchart's (cited in Durrheim, 2004) contribution to the debate on the distinction between basic and applied research and claims that all research is action-orientated (and therefore applied), but can be divided into three types of research, namely fundamental, intervention and strategic research. Fundamental research focuses on knowledge of scientific significance and may lead to new technologies. Intervention development and evaluation research creates and assesses intervention technologies. Butchart (1998) distinguishes strategic research from that of fundamental and intervention research by defining strategic research as "research that generates knowledge about specific needs and problems (these include specific social conditions and systems) with a view to eventually solving or reducing the problem through further development and evaluation" (p. 42).

This applied research aims to contribute towards the practical issue of the relevance of the principles of existentialism for a woman's search for meaningfulness, while living with HIV/AIDS, imbedded in the multi-realities of the context within which she exists. The purpose of this research is to provide information about the practical existential experiences of one participant who lives within a South African context, where millions of other people are also suffering from HIV/AIDS. The participant wishes to share her practical experiences of making meaning, while suffering from HIV/AIDS, with other individuals and communities, which might contribute to their journeys of creating meaning in their own suffering.

The kind of information required and the analytic strategy that is to be followed in this study are *qualitative*. Data is collected in the form of spoken language through interviews and analysed by identifying and categorising themes. Qualitative methods were applied in order to study selective issues in-depth, openness and detail as they are identified and it is then attempted to understand the categories of information that emerge from the data. By identifying themes, the researcher attempted to build up a detailed picture of the experiences of the participant. These themes were then integrated with propositions of existentialism imbedded in the context from where a thick description was formulated.

1.3. Epistemological approach

Norman Denzin and Yvonna Lincoln (2000, p. 18) state that, "the gendered, multiculturally situated researcher approaches the world with a set of ideas, a framework (theory, ontology) that specifies a set of questions (epistemology) that he or she then examines in specific ways (methodology, analysis)". Accordingly, the researcher who wrote this manuscript assumes that there is no clear window into the inner life of an individual. Any gaze is always filtered through the lenses of language, gender, social class, race and ethnicity. From the perspective of this researcher, there are no objective observations, only observations socially situated in the worlds of and between the observers and observed (Denzin & Lincoln, 2000).

The perception-forming assumptions and highly abstract principles (Bateson, 1979) that form part of the researcher's interpretative framework has *post-modernistic* and *constructionist* trends. Sey (1999) defines postmodernism as "a broad term for many different approaches that set themselves up in opposition to the coherence and rationality of the modern world. Postmodernity is the cultural setting within which postmodernism has been able to flourish" (p. 462).

Postmodernism is anti-reductionist and pluralist, preferring the decentred knowledge available "not only to a central knowledge commissar but also to people who engage with the world from the irreducible perspectives of their own experience" (Agger, 1991, p. 24). According to Agger (1991), postmodernism rejects the possibility of presupposition-less representation, instead arguing that every knowledge is contextualised by its historical and cultural nature. Postmodernism rejects the view that science can be spoken in a singular voice.

The philosophical postmodernist, Lyotard (1984) rejects totalising perspectives on history and society which he calls "grand narratives" and which he suspects of "self-aggrandising" motives. He maintains that one cannot tell large stories about the world but only small stories from heterogeneous "subject positions" of individuals and plural social groups. According to Bakker (1999),

The post-modern world is characterised by a process of decentring and of a multiplicity of relationships where each individual forms part of multiple communities and cultures, and where what is to be considered to be real varies between these contexts. (p. 169)

People are exposed to different realities and move continuously between them. Humans do not have access to one objective reality, only multiple constructions of reality by multiple observers. Maturana (1975) proposes the concept of "multi-verse" as an alternative for an objective, unitary universe waiting to be discovered. In a postmodern world there are no grand narratives of truth left; only multiple processes of collaborative knowing. Knowledge and reality is co-constructed by human interaction. Postmodern thought moves towards a relational, fluid view of self, mind,

emotion and sensation as well as related constructs. The social world is examined from multiple perspectives of class, race, gender and identifying group affiliations (Bakker, 1999).

It is essential to Jameson (1991) to grasp postmodernism as a "cultural dominant: a conception which allows for the presence and co-existence of a range of very different, yet subordinate, features" (p. 2). Eskell-Blokland (2005) suggests, "Because postmodernism is not a paradigm in itself, and if it is accepted as a historical perspective, a cultural dominant, seeking to present diversity and multiplicity, it can inclusively embrace aspects of modernism, positivism and reflexive paradigms" (p. 140). She states that although postmodernism becomes

a historical term...certain themes...[are] almost synonymous with postmodernism...[and] include a rejection of...the grand-narrative or meta-narrative...[as well as] the totalising tendency of positivism into universal truths, a focus on the cultural other, the oppressed, marginalised and the local.

The epistemological stance of the researcher moves from a scientifically objective and detached observation of the positivistic position towards a suspicious, overt political, and constructionist position of the postmodern, in a more interpretative and reflexive orientation... (Eskell-Blokland, 2005, p. 138)

Sey adds to this:

Where interpretation in the empirical model was a transparent method of understanding phenomena in the world, it became in the post-modern conception an end in itself rather than a means. (Sey, 1999, p. 464)

During therapy, themes such as being HIV positive, suffering, death, suicide, isolation, meaninglessness, meaningfulness, being-in-the-world, relationship with others, and values were co-created by the client and therapist, through language. The therapist shared the life stories of Victor Frankl and Rollo May as well as the values of existentialism, with the client. Although the client's constructions of existential experiences of her reality of being HIV positive, is unique, she also experienced a sense of universality (Yalom, 1995). She felt inspired by their narratives

and a need evolved to create meaning in her life as well as to install hope through the construction of meaning. Although the approach to this research is constructionistic, the researcher engaged in the grand narrative of existentialism to the extent in which existential concepts are useful for this study.

1.4. Overview of present study

Although HIV/AIDS is a global epidemic, it impacts on every individual's life in a unique way, also taking into account that there are multi-realities in the multi-verse where everything is connected with everything else. This research is an in-depth study of a woman's unique existential experiences and her creation of meaning while living with HIV/AIDS, imbedded in the multi-contexts within which she exists. The research plans to explore and describe a woman's search for meaningfulness - while being HIV positive - and to relate these findings with key propositions of existentialism. The approach of the study will be a post-modernistic attitude with constructionist trends.

The study begins with chapter 1, an introduction to the phenomenon being investigated. The motivation for the research and the objectives of the research are explored. Epistemological attitudes are language in order to communicate the researcher's approach to the study.

Chapter 2 describes the researcher's exploration of a range of theoretical resources concerning relevant contexts within which the participant exists. That is, the biological, psychosocial, gender, cultural and political contexts. A literature review is provided and focuses on the reciprocal process and relatedness of the different contexts, which impacts on each other.

Meaning making from an existential viewpoint is explored in chapter 3. Key propositions of existential perspectives, which are elaborated on, are: being-in-the-world, self-awareness, freedom and responsibility, creation of meaning, meaningful relationships, values, anxiety, awareness of death and non-being, as well as a sense of a Higher Being. Included in this

chapter is particular reference to the experience of meaning making, while living with HIV/AIDS, from a woman's perspective.

Chapter 4 consists of a discussion on the methodology and ethical considerations of the study. Because of the in-depth character of the study and the sensitivity of the topic, the researcher is cautious of ethical considerations in order to respect the participant's privacy, needs and experiences. There will be an elaboration on the ethical values of the researcher as well as precautions taken, in order to protect the participant. This chapter also describes the qualitative nature of the study including the selection of the participant, as the case being studied. Methods of data collection as well as the steps in analysing the data are discussed.

An integrative reflection and description of the themes derived from the participant's search for meanings, integrated with an existential perspective on the phenomenon imbedded in their contexts, are described in detail in chapter 5. The participant's experiences of being HIV positive, making meaning thereof and living with the disease, are imbedded in the multi-contexts within which she exists.

The conclusions of the study are reflected upon in chapter 6, which is followed by some recommendations.

Nevertheless, it is important for the researcher to state that in this study, "More will be pursued than was volunteered. Less will be reported than was learned" (Stake, 2000, p. 441). The next chapter describes the rich context within which the participant exists in order to give a thick description of the case.

CHAPTER 2: WOMAN WITH HIV/AIDS IN CONTEXT

2.1. Introduction

According to literature (Evian, 2000; UNAIDS, 2004; Whiteside & Sunter, 2000) HIV/AIDS is a global pandemic that has reached every corner of the globe, although the prevalence of the disease seems to be under-reported and under-diagnosed (Lachman, 1995). Problems that have been identified in the existing data include geographic bias, non-representativeness, testing bias and problems surrounding the clinical case definition of AIDS. Statistics can differ radically from source to source, which currently makes it difficult to make a realistic assessment of the actual status of the HIV/AIDS condition in the country. "However, some form of reliable predictive statistics is needed in order to prepare for a possible pandemic within the life span of the majority of South Africans" (Evans, 2002, p. 15).

According to Harrison, et al. (2000), HIV/AIDS is the world's fastest-growing epidemic and no vaccine has yet been invented to cure the disease. It is unlikely that an effective vaccine against HIV infection will be widely available in the next ten years and it is even less likely that a cure will be found in this time. Thus, the lived experience of HIV/AIDS, particularly in sub-Saharan Africa, requires urgent attention (Love Life, 2001). Because there is no precedent for HIV/AIDS, there are no precedents for coping with the issues surrounding HIV/AIDS on both personal and societal level (Tegius & Ahmed, 1992). Most of the research on people living with HIV/AIDS is focused on medical factors describing transmission and biology. Only a small number of theoretical studies and empirical research begin to explore how people living with HIV/AIDS cope (Evans, 2002).

Interconnected systems surrounding the individual who lives with HIV/AIDS, form reciprocal patterns of interrelatedness in the context within which the individual exists (Becvar & Becvar, 2000). HIV/AIDS threatens food security, productivity, human resource availability and development (UNAIDS, 2004). It severely leaves its mark on the individual and family and this impact reaches the macro-economic level as well. According to Louw (1994), the AIDS

scenario in Africa is not related to individuals only. "It warns that AIDS in Africa is becoming a community and systemic problem" (p. 122). Therefore, an integrative discussion of the biological, psychosocial, socio-cultural and political context follows.

2.2. Biological context

AIDS is, according to Sadock and Sadock (2003, p. 371), a "lethal neuromedical disorder associated with infection by viruses of the Retroviridae family known as human deficiency viruses (HIV)". *AIDS* is the acronym for Acquired Immune Deficiency Syndrome. Van Dyk (2005) notes that the disease is acquired and caused by the human immuno-deficiency virus (*HIV*) that enters the body from outside. The body's natural ability to defend itself against infection and disease is called immunity. A deficiency is the weakening of the immune system so that it can no longer defend itself against passing infections. A collection of specific signs and symptoms that occur together and are characteristic of a particular condition is called a syndrome. *AIDS* is therefore a gathering of many different conditions that manifest in the body and can be defined as "a syndrome of opportunistic diseases, infections and certain cancers – each or all of which has the ability to kill the infected person in the final stages of the disease" (Van Dyk, 2005, p. 4).

HIV-1 and HIV-2 have been identified as two major strains of HIV. HIV-2 is mainly confined to West Africa, while HIV-1 is more geographically extensive (Webb, 1997). Both strains present similar clinical manifestations, although the onset of immune deficiency appears to be more gradual in HIV-2. There may be other subtypes of HIV, which are now classified as HIV-O (Sadock & Sadock, 2003). Recent reports suggest that there is a possibility of the existence of a third type of HIV, discovered in the Cameroon (Goldstein, 2004).

HIV has been identified in various body fluids and is especially highly concentrated in blood, semen, as well as in vaginal fluid (Whiteside & Sunter, 2000). HIV infection is therefore primarily transmitted by sexual intercourse; HIV infected blood passing directly into the body of

another person; and by a mother to her baby during pregnancy or childbirth or as a result of breastfeeding (Sadock & Sadock, 2003). This transmission is more likely to happen if the virus is present in sufficient quantities, the virus gets access into the bloodstream and the duration of exposure is long enough. For infection to happen the virus must find a way to enter the bloodstream and must take hold (Whiteside & Sunter, 2000). Biology makes women automatically and physiologically vulnerable to contract HIV/AIDS (Evans, 2002). Male to female transmission is more likely because a woman has a larger surface area of her genital tract exposed to her partner's sexual secretions, during vaginal intercourse, than does a man. HIV concentration is generally higher in male semen than in a woman's sexual secretions (Evian, 2000).

The health of the HIV positive individual depends on the condition of her immune system at a particular time, for the HI virus attacks and kills mainly the CD cells. An indication of the current status of the HIV positive person's immune system can be obtained by measuring the actual number of CD cells. The CD4 count is the best predictor of how easily opportunistic infections will be able to take root in an HIV positive person. The CD4 count will give a diagnosis of the health status of an HIV positive person (Evian, 2000; Sadock & Sadock, 2003). According to Van Dyk (2005), viral load and CD4 cells have an inverse seesaw relationship, and if considered together, can predict whether a person's journey towards a final phase of AIDS will be rapid or slow.

A high viral load will go hand-in-hand with a lower CD4 cell count, because the virus destroys the CD4 cells. A lower viral load will go hand-in-hand with a higher CD4 cell count, because if there are fewer viruses in the blood, the immune system gets a chance to build up CD4 counts again. (p. 38)

Disease succession will therefore depend on the viral load and on the CD4 count in the blood. The higher the viral load, and the lower the CD4 cell count, the easier it will be for infections to attack the body. It is possible that a HIV positive person with a low viral load and a high CD4 count can stay healthy for many years, because her immune system is still strong enough to

fight the infections. A normal CD4 count in non-infected individuals is approximately 800-1200 cells/mm³ (Whiteside & Sunter, 2000).

According to Van Dyk (2005), HIV infection can theoretical be divided into different phases, although these phases are not separate and distinct with easy identifiable boundaries (Evian, 2000). HIV infection can be divided into the following phases:

2.2.1. The primary infection phase (Acute Seroconversion Illness)

The acute phase of HIV infection begins as soon as seroconversion has taken place and is also conceptualised as, acute seroconversion illness (Evian, 2000). "Seroconversion means the point at which a person's HIV status converts from being HIV negative to positive" (Van Dyk, 2005, p. 40). Seroconversion usually occurs approximately six weeks after infection with the HI virus. The viral levels reach a steady state (set point), 16-24 weeks after infection (Evian, 2000).

2.2.2. The asymptomatic latent phase of the disease

The asymptomatic phase of silent infection is usually related with a CD4 cell count of between 500 and 800 cells/mm². During this stage an infected person displays no symptoms and is often unaware that they are carrying the HI virus. The CD4 count usually decreases by 40-80 cells/mm³ per year (Evian, 2000).

2.2.3. The minor symptomatic phase

When a CD4 cell count reaches between 350 and 500 cells/mm³, it is called, the minor symptomatic phase (Evian, 2000). In this phase of infection, minor and early symptoms of the

HIV disease usually begin to become evident and more identifiable. The individual is generally able to carry on with her normal activities, despite being symptomatic (Van Dyk, 2005).

2.2.4. The major symptomatic phase

The phase that follows the minor symptomatic phase is called the major symptomatic phase, which is usually associated with a CD4 cell count of between 200 and 350 cells/mm³. Major symptoms and opportunistic diseases begin to appear as the immune system continues to deteriorate. The onset of vaginal candidas and recurrent herpes infection are commonly the first clinical signs of advanced immune deficiency (Evian, 2000). During this phase, the person will most possible have been bedridden for up to 50% of the day during the past month (Van Dyk, 2005).

2.2.5. The severe symptomatic phase (AIDS defining conditions)

AIDS patients usually have a very high viral load and severe immune deficiency with a CD4 cell count of below 200 cells/mm³. It usually takes about 18 months for the major symptomatic phase to develop into AIDS. In the final stage of AIDS, the symptoms of the HIV disease become more severe. "The presence of any serious opportunistic infection is a sign that the body is not coping immunologically" (Evian, 2000, p. 32). The AIDS patient will usually have been bedridden for more than 50% of the day during the past month. Although people with AIDS generally die within two years, antiretroviral therapy and the prevention and treatment of opportunistic infections may extend this period (Van Dyk, 2005).

According to Louw (1994), AIDS is a contagious, transmissible and fatal disease with radical implications. The virus is sly and unpredictable. Louw (1994) notes that AIDS is a behavioural disease for "it radicalises human behaviour to the point where choices and responsibility obtain a new dynamic meaning" (p. 127). Although Van Dyk (2005) coincides with Louw (1994) when

she states that, "HIV/AIDS has become one of the most destructive plagues in history. It is a monster that threatens to destroy our society because it is changing the rules by which we live" (p. 3), she nevertheless believes that, "HIV/AIDS has become a chronic treatable disease rather than a progressive fatal disease" (p. iii). Since this disease and lifestyle are so mutually affected by each other, it is appropriate to discuss the psychosocial context of a woman living with HIV.

2.3. Psychosocial context

HIV/AIDS will not only impact on the biomedical field, but will also affect the *psychosocial realities* of people touched by the virus. The problems associated with HIV/AIDS transcend the medical diagnoses and treatment of the disease. In reflecting upon the psychological context of women with HIV/AIDS, it is clear that there is a shortage of specific research in this particular field of study (Evans, 2002). Although the literature has begun to examine important issues related to people living with HIV/AIDS, research on the idiosyncratic meanings and experiences of people living with HIV/AIDS is very limited. A study of the literature has identified significant gaps, particularly in the experience of living with HIV/AIDS within the South African context (Goldstein, 2004).

Psychosocial realities of any individual who is touched by the virus will significantly be affected. Psychological reactions of shock and turmoil to the diagnosis of HIV/AIDS are often present as part of the initial impact of the disease on an individual's life (Evans, 2002). Many of the issues particular to HIV infection have a bearing on the psychological health of the individual infected. These issues may include the terminal nature of the infection, prolonged adjustment reaction, anxiety, social stereotyping and interpersonal problems as well as feelings of denial, anger, depression and guilt (Jordaan, 1989).

Uncertainty also seems to be inextricably part of the existential experiences of individuals who are going through the different HIV/AIDS-related phases. Uncertainty often emerges while an individual is waiting for HIV-test results, or by doubt caused by fear of how a significant other

may respond to a person being HIV positive. Studies of HIV-related uncertainty have shown that uncertainty is negatively associated with quality of life and psychological adjustment (Brashers et al., 1999). Experience of uncertainty in illness and ambiguous symptoms, complex systems of treatment and care, insufficient information about diagnosis and progression, may all evidence symptoms of anxiety and depression. Stigmatisation may lead to a lack of social support, resulting in isolation, which in turn may lead to depression and anxiety (Louw, 1994). Dansky (1994) describes the "epistemology of stigma" as "the complementary, dual symbolisation of moral and physical chaos embodied in a reciprocal interrelationship" (p. 38). Many of the issues particular to HIV infection have a bearing on the psychological health of the infected individual. Amongst African women, these include stereotyping and marginalisation (Evans, 2002).

Research suggests that *depression* is a typical psychological outcome that people with HIV infection face (Sadock & Sadock, 2003). Depression may result from a variety of factors such as feelings of lack of control over one's fate, changes in a person's self image, concern over the implications of the illness on personal relationships and circumstances, exposure to stigma and possible resulting abuse, and the perceived and real risks of disclosure (Hedge, 1990; Van Dyk, 2005). According to the Southern African AIDS Trust (2000), disclosure can be accompanied by the benefits of helping people to accept their HIV positive status, ease their access to medical services, help people protect themselves and others, reduce the stigma and discrimination surrounding HIV/AIDS as well as encouraging the person's loved ones to plan for the future. Disclosure may, however, also be accompanied by negative consequences such as difficulties in relationships, rejection, and the conviction that people are constantly judging one (Van Dyk, 2005).

As the crisis transpires, meaningfulness of activities, of human relationships and of life is questioned (Presti, 1990). Individuals who are HIV positive often begin to question whether meaning can be created in their suffering and search whether it is possible to make meaningful decisions as well as to act purposefully under conditions where death is the only available option (Louw, 1994). Suicidal behaviour and thoughts within the HIV-infected population

indicate a high risk with regard to these individuals suicidality (Van Dyk, 2005). Researchers recognise that the frequency of suicidal tendencies as well as completed suicides is common in individuals who are HIV positive. Avoidance coping strategies, deprivation, and/or withdrawal from social support and fear of disfigurement appear to contribute towards the suicidal impulse (Hedge, 1990; Jordaan, 1989).

HIV positive individuals also frequently experience *anxiety* due to the uncertain prognosis and course of the illness, as well as the threat of death implied by this infection (Sadock & Sadock, 2003). The risk of infection with other diseases or infecting loved ones with HIV contributes to the experience of anxiety. HIV positive individuals tend to fear social, occupational, domestic and sexual hostility and rejection. Abandonment, isolation, physical pain and the fear of dying without dignity, adds to the experience of anxiety in HIV positive individuals (Hedge, 1990). Their inability to change circumstances and consequences of HIV infection (while experiencing a deteriorating ability to function efficiently together with their loss of physical and financial independence) contribute to an individual's levels of anxiety (Van Dyk, 2005). The effects of medication, the HIV statuses of the infected person's partner as well as the partner's ability to cope with the implications are contributing factors to the incidence of anxiety in people infected with HIV/AIDS. In the case of South African women, concern over their children may also contribute significantly to the incidence of anxiety. The implied threat in self-disclosure and possible societal ostracisation precipitate further anxiety in many South African women (Evans, 2002).

While the experience of HIV/AIDS is deeply personal and intimate, it is inextricably bound up, shaped, given voice and responded to through the lenses of gender, culture and politics.

2.4. Gender based context of HIV/AIDS

Evidence (Henderson, 1996; UNAIDS, 2004) indicates that in sub-Saharan Africa, there are more *women* infected with HIV/AIDS than men. Fifty-five percent of infected adults are women,

thus translating into six HIV positive women for every five infected men. Some of the major contributing factors that cause women to be so vulnerable include biological, political, economic, socio-cultural, religious and gender factors (Squire, 1993). Historically powerful patterns of gender inequality, discrimination and the neglect of female sexuality are fundamental driving forces of the AIDS epidemic in South Africa (Susser & Stein, 2000).

According to Gupta (2001), gender is a social and cultural-specific construct that refers to the widely shared expectations and norms within a society about appropriate male and female behaviour, characteristics and roles. It defines the way in which women and men interact with one another and distinguish them from each other. Wilton (1997) contends that although there are significant differences between different cultural beliefs regarding gender, it is fairly consistent across cultures that there is a distinct differentiation between women and men's roles, access to productive resources and decision-making authority. Men are seen as responsible for the productive activities outside the home, while women need to take responsibility for reproductive activities inside the home. Women have less access and control over productive resources, such as income, land credit and education. Grundlingh (2001) points out that women in South Africa in particular are socio-economically exposed to HIV infection.

Wilton (1997) observes that biology is further complexified by the social meanings and understandings intimately connected and intertwined with gender and sex. She proposes that sex is not merely an instinctive, biological behaviour but is socially constructed in complex and symbolic ways. She suggests that class, gender, race, age and nationality influence the manner in which one chooses to engage with sexual partners and impact on the agency and power one has in terms of one's sexuality and sexual practices. HIV positive women bear the double burden of being a woman as well as being infected. In many societies, being socially ostracised, marginalised, stigmatised and isolated are potential consequences of revealing one's HIV status (Esu-Williams, 2000; Gupta, 2001).

Power also seems to be fundamental to sexuality and gender. The unequal power balances in gender relations that favour men, reflect unequal power balances in heterosexual interactions. Male pleasure supersedes female pleasure and men have greater control than women over when, where and how sexual intercourse takes place (Gupta, 2001; Wilton, 1997). This power imbalance that defines gender relation and sexual interactions, also affects women's access to and use of treatment and services (UNAIDS, 2004).

Gender is further interwoven with culture, something that plays a particularly principal role in the construction of meaning, while living with HIV/AIDS. An individual who is HIV positive can also not be seen in isolation from the political context within which she lives. Therefore a discussion on the cultural and political context within which the participant exists is necessary.

2.5. Socio-cultural context

Eskell-Blokland (2005) refers to culture as "that which evolves in relationship between people" (p. 74). She suggests that

culture from this perspective consists of integrated and complex systems of values, beliefs and rules of conduct for human social behaviour as a result of networks and communication ... and therefore is an essentially human process outcome, socially constructed, and is not identified by single factors such as race, ethnicity or language groups. (p. 74)

Culture, according to Eskell-Blokland (2005), can be perceived as dynamic. She notes that, "it is the collective mind, which determines the individual sense of self, rather than the sum of individual selves that determine the culture" (p. 130).

Vontress (1996) points out that all people are multicultural in the sense that they are all products of many cultures. However, in working with cultural diversity it is essential to recognise simultaneously the commonalties and differences of human beings. Cross-cultural work does

not intend to teach specific interventions for each culture, but for each individual with her unique construction of reality. Eskell-Blokland (2005) writes that although

particular cultural characteristics for specific socio-cultural contexts have been identified ... it does not necessarily mean that these characteristics are present in any 'real' sense. These characteristics may be universally present in all human societies, but the difference and significance lies in the values attached to these characteristics by different cultures. (p. 130)

Louw (1994) suggests that the African worldview includes understandings and social scripts surrounding both health and illness. The spiritual dimension plays a fundamental role in the understanding of illness within the African tradition and needs to be understood corporatively: "man is part of a social order in which living energy is linked to cosmic and religious powers which give meaning to everyday existence" (p. 23). Louw (1994) therefore expresses the importance of a holistic approach to the illness/health problem in an African context. The African worldview perceives health as a symbol of a healthy relationship with the environment. Illness thus represents a destabilisation of the societal order and harmony and is perceived as a consequence of disrespecting the moral codes of society, cosmic ties and ties within the community. Recovery is only achieved when the ties with the cosmic world and the community are restored. In contrast, the Western worldview dictates an understanding of illness that is governed by notions, which view the human body as a system: when disease occurs it usually relates to a breakdown in a part/parts of the system. Thus, treatment focuses on diagnosis, prognosis and treatment where medication is usually prescribe. Goldstein refers to Brandt (as cited in Goldstein, 2004) and suggests that the concept, disease, is rife with meanings:

By demonstrating the process by which biology and culture interact, the precise nature of social construction of disease may be revealed. This is not to argue that disease is purely a relative phenomenon, merely constructed by certain privileged knowledge. Rather, it suggests that so complex a phenomenon as disease cannot be understood outside the culture in which it occurs. The biological world is fundamentally transformed by culture and politics. (p. 45)

Although Eskell-Blokland (2005) engages with people's indigenous, non-western-ness in her research, she perceives indigenous people of South Africa as not being "... homogenous in traditions, beliefs, customs, language and other possible measures of culture" (p. 24). She further exposes local African cultural conceptualisation in her doctorate thesis, namely: *Voice to the silent: An ecology of local knowledge in psychology*. Eskell-Blokland (2005) reminds the reader that the role of cultural variations needs to be acknowledged, understood and addressed.

Evans (2002) writes that the odds against women in Africa seem to be great due to traditional cultural beliefs. African women still live largely in a world where they first have to prove their worth by being married, having children and caring for their families (Esu-Williams, 2000). Within the social and cultural contexts, women affected by HIV/AIDS are often faced with no means to deal with the denial of their basic rights, including the right to property, to their children and to produce the means to their own livelihood. Women's economic dependence increases their vulnerability to HIV as it makes it more likely that they will exchange sex for money, less likely that they will succeed in negotiating protection and less likely that they will leave a risky relationship (Gupta, 2001).

Even though Van Dyk (2005) emphasises the importance of traditional behaviours, she warns against those customs that are harmful to people's health. She stresses the danger of customs like cleansing rituals, inheriting a wife, impregnation of brother's wife, female genital mutilation and the practise of dry sex, as these are all risks for becoming infected with HIV. During cleansing rituals, whereby a widow has to have sexual intercourse with a close relative of her deceased husband's spirit, HIV infection might occur (Hicksen & Mokobo, 1992). The custom of inheriting the wife of a deceased brother, who might have died of AIDS, may have devastating implications for the brother and any children resulting from the union. The impregnation of an impotent or sterile brother's wife might also result in HIV infection. The use of sex to express hospitality where the host offers his wife or sister to a visiting guest puts a woman in danger of contamination (Mbiti, 1969). A woman might also be infected with HIV during female genital

mutilation or circumcision. The practise of dry sex to heighten sexual sensation for men puts a woman at risk for becoming infected with HIV, more easily (Van Dyk, 2005).

According to Gupta (2001), a culture of silence that surrounds sex is present in societies within the African context, which dictates that women are expected to be ignorant about sex and passive in sexual interaction. This makes it difficult for women to be informed about risk reduction and for them to be pro-active in negotiating safer sex. Women often feel powerless to protect themselves against HIV infection (Evans, 2002). Women, so far, have been passive in sexual relationships with little participation in decision-making or suggestions relating to their role in sexual activity (Wilton, 1997). Polygamy in sub-Saharan Africa is widely practised: when a husband seeks a new, often younger wife, he may have sexual contact with a number of other women and thus bring HIV home (Husken, 2001). The custom of lobola (when a man pays his bride's father in order to marry her) may imprison a woman without the option of terminating the relationship if it should become necessary. Once the bride has been paid for, the woman cannot leave her husband. Enlightenment and liberation is thus essential for women, who in turn can play a vital role in persuading partners to employ safer sexual practices aimed at reducing infection risks (Henderson, 1996).

Physical violence and the fear of abandonment also act as significant barricades for women who need to negotiate the use of a condom, discuss fidelity with their partners, or leave relationships that they perceive to be risky (Gupta, 2001). According to Van Dyk (2005) there are perceptions on condom use, which makes the use thereof, unpopular. Some Africans believe that

the flow of fluids involved in sexual intercourse and reproduction represents the exchange of 'gifts of self' which they regard as being of the utmost importance in a relationship. The use of condoms is thought to block this vital flow between two partners, and such blockage is seen as preventing fertility and also causing all sorts of illnesses. (p. 123)

According to Esu-Williams (2000), HIV/AIDS is traditionally still associated with sexual misbehaviour and promiscuity. HIV positive women face stigmatisation and are more likely than men to be blamed and abandoned by their families. Community stigma contributes to why women refuse to be tested for HIV/AIDS. They foresee difficulties in terms of facing partner rejection, stigma and psychological stress as a result of a positive HIV diagnosis (Louw, 1994). The socio-cultural context of an individual living with HIV/AIDS is interwoven with the political environment within which she lives. Culture seems to influence perceptions, which can determine the content of policies on HIV/AIDS. Therefore a discussion on the political context follows.

2.6. Political context

According to Grundlingh (2001), it is important to examine the spread and understanding of HIV/AIDS within the South African political context. He remarks that in South Africa, HIV/AIDS became known during the apartheid political regime, firstly as a homosexual disease, a disease of drug users and later on as a disease afflicting the black communities. There was consequently no urgency in addressing this infection. It exposed and intensified social prejudices, stereotypes and economic inequalities, discriminatory practises and political injustices. The history of HIV/AIDS in South Africa is rooted in a framework couched in a discourse of deviancy and scapegoats. Gumede (2005) agrees with Grundlingh (2001) when he contends that

the Apartheid regime had been deaf for calls for actions, seeing AIDS largely as a disease that affected gays and blacks, constituencies the previous government was not particularly interested in, and was most prevalent among migrant workers from the southern African region. (p. 152)

According to Evans (2002), the official ANC policy on HIV/AIDS in the current government of South Africa seems to be controversial. "This is fuelled in particular by President Mbeki's public flirtations with dissident theories that refute the fact that HIV causes AIDS. He and his cabinet

tend towards blaming AIDS on poverty and the Apartheid legacy" (p. 17). According to Gumede (2005), President Mbeki has been seduced by Rasnick and Duesberg whom are of the opinion that "AIDS in Africa is just a new name for the disease of poverty caused by malnutrition, poor sanitation, bad water, parasites and so on" (p.159). William Gumede (2005) follows that Health Minister, Manto Tshabalala-Msimang, drew hoots of derision when she famously announced that people with AIDS should preserve their health not with drugs, but with a diet of garlic, lemon, olive oil and the African potato. "President Mbeki's controversial health minister ... enthusiastically prescribed an alternative therapy that sounded more like a salad dressing than treatment for a sexually transmitted disease that kills around 600 South Africans a day" (Gumede, 2005, p. 150).

There also seems to be controversy around the government's perception on the epidemiology of HIV/AIDS in South Africa, which denies the growing rate of the epidemic in the country by referring to outdated statistics (Evans, 2002). A controversial debate emerged in the media because of the ANC's questioning of the seriousness of HIV/AIDS and whether it was receiving too much funding. Private health care in South Africa amounts to approximately 70% of the total national budget, yet only about seven million of the country's 44 million citizens can afford private health insurance (Gumede, 2005).

According to Evans (2002), the ANC initially refused to offer free anti-retroviral drugs to the South African public, such as the AZT drug for AIDS-infected pregnant mothers. The government argued against the use of AIDS drugs such as Nevirapine, stating that they are too expensive and potentially dangerous (UNAIDS, 2004). Only, in a major policy shift in April 2002, the government said it would provide free AIDS drugs and counselling to victims of sexual assault, as well as pregnant woman. It, however, took years of foot dragging and obfuscation before these drugs have been accessible to people living with HIV/AIDS in the country. Gumede (2005) notes that

...the South African government finally enrolled out anti-retroviral drugs that could save the lives of millions at state hospitals two weeks before voters went to the poles in April 2004. The long awaited loan to distribute ARV's to an estimated five million people has

been approved in November 2003, but due to what officials claimed were 'capacity constraints', patients had to wait another five months for the first drugs to reach them.

(p. 150)

Evans (2002) contends that, "in reality, it appears as if the ANC policy on AIDS is nonsensical, disjointed and without definite leadership" (p. 18). According to Gumede (2004), President Mbeki denied in an article in the *Star* (April 2002), that there was a lack of government leadership on AIDS. He said: "Perhaps we are not communicating that message loud enough. But I think there's been very strong leadership on the matter. It is critically important that I communicate correct messages". Gumede (2005) also contends that since then,

South Africa has increasingly channelled funds into AIDS programmes, albeit at the cost of poverty alleviation or opening their pockets to trade with poorer countries.

Development funding is now earmarked almost exclusively to halt the infection rate and treat victims. (p. 172)

Poverty and depressed socio-economic conditions exist in Africa and other Third World countries (UNAIDS 2004). HIV/AIDS tends to be more prevalent in communities living in these depressed socio-economic conditions. Family and social lives are dislocated because of high unemployment that forces men to migrate to cities (Wilton, 1997). Involuntary migration, enforced by the Apartheid political regime, inevitably caused casual and extra-marital sexual encounters, which still seems to be the case (Susser & Stein, 2000). According to tradition, women have a low status in society and are denied the authority to negotiate safe sex practises. Poverty further forces women to sell their bodies for sex. People also live in extremely bad conditions and have limited access to health services (Wilton, 1997). The use of contraceptives is low while the prevalence of sexually transmitted infections is high. There are widespread illiteracy and poor education. Common alcohol abuse lowers the thresholds of inhibition and compromises sensible decision-making (UNAIDS, 2004). It seems that the old traditional moral and social values that created cohesion and mutual help in the communities are disintegrating. "The community is often subject to famine, wars, conflict, crime and high levels of corruption" (Van Dyk, 2005, p. 35).

2.7. Conclusions

This chapter attempted to contribute to an understanding of the biology of HIV/AIDS and inextricably linked psychosocial components to it. It explored the manner in which initial diagnosis impacts on one's sense of self as well as one's responses to HIV/AIDS. Finally, it explored the social construction of HIV/AIDS by especially focussing on the important impact of gender, culture and politics on the lived experiences of the disease. The next chapter will look at the existential experiences of a woman living with HIV/AIDS according to existentialism. The focus will be on the creation of meaning while living with HIV/AIDS.

CHAPTER 3: MEANING FROM AN EXISTENTIAL PERSPECTIVE

This chapter attempts to explore and understand the concept of meaning, the need it fulfils and the creation thereof. Meaning will primarily be examined from an existential philosophical point of view and the propositions of existentialism will be enlightened. Western and African worldviews, in relation to meaning making, will be examined by exploring the intersection of culture with personal meaning systems. Meaning in suffering, specifically in living with HIV/AIDS, will be explored.

3.1. Describing meaning

The experimental existential psychologists, Janoff-Bulman and Yopyk (2004) coincide that there is little clarity or consensus regarding *meaning*, although much has been written on people's need for meaning. "When psychologists discuss meaning, then, it is often unclear whether we are even talking about the same phenomenon" (p. 122). Stern (1971) notes that a philosophical definition of meaning is unattainable, as a definition is by very nature a statement about meaning. Meaning is presupposed in all definitions and therefore in itself undeniable, for the meaning of a sign is what it stands for and the interpretation thereof constructed by each individual in a unique way. In this study, meaning will be perceived and explored as an individual's (in relationship with others) contextual existential experience of constructed reality.

According to Redekopp (1990), existentialists suggest meaning, "to be components of the human condition that powerfully influence human thought, emotion and action" (p. 16). A deep contemplation on the meaning and purpose of human existence characterised Victor Frankl's whole life. "Man's heart is restless unless he has found, and fulfilled, meaning and purpose in life" (Frankl, 1969, p. 31). He contends that we are only fully, what we have been created to be, when we live and move and have our being, in the dimension of meaning. He believes that the human being primarily needs to be motivated by a will to meaning.

Ronnie Janoff-Bulman and Darren Yopyk (2004) address two primary understandings of meaning derived from years of research with individuals who had experienced extreme negative events. It is proposed that there are two quite distinct quests for meaning in human experience: One revolves around comprehensibility, the other around significance. Survivors of traumatic life events confront questions about how to make sense of events in their world (comprehensibility) and then address issues regarding the construction of value and worth in their life (significance). Although these two types of meaning may be interdependent, they note that in the case of trauma survivors, it is the recognition of meaninglessness in the first sense - incomprehensibility - which appears to serve as a catalyst for the creation of meaning in the second sense - significance. Survivors move from recognition of randomness in the world to the creation of value in their own lives. "As painful as it is, trauma is a route to value creation. Surely it is not the only route, but paradoxically; it is one very effective path" (Janoff-Bulman & Yopyk, 2004, p. 134). They plead for a discovering of alternative routes, so that we may learn to live lives of greater depth and commitment in the absence of traumatic life experiences.

3.2. Western and African worldviews on meaning

Western and African worldviews in relation to meaning making are examined by exploring the intersection of culture with personal meaning systems (Marsella & White, 1982). Victor Frankl (1969) proposes that values are "meanings which are shared by human beings across society and ... throughout history" (p. 55). According to Bruner (1990), meaning is a culturally mediated phenomenon that depends upon prior existence of a shared symbol system. The form which meaning takes on is influenced by one's participation in symbolic systems of culture. He argues that although meaning may be experienced as private, it affects a public communal artefact. Eskill-Blokland (in press) notes in her writing on an *Indigenous perspective on psychology*, that in the African tradition, importance is placed on the integration of the individual person into the social community, which is different from the Western emphasis on independent functioning. In the traditional African view, the individual is seen as a relational being that is always part of the community, with the notion that nothing and no one can exist alone. All of life is included in this

relational perspective where belongingness and affiliation are considered to be essential and rituals and rites of passage perceived as community events. Eskell-Blokland (in press) further writes that the self can only be understood in relation to others. In this complex interdependence a person is constantly negotiating a healthy balance between individual and collective needs. Communalism and collectivism in the African tradition value the concept of self as a being that lives in harmony and interdependence with others.

Fabry (1968) suggests that the belief in meaning in life may be facilitated by a specific worldview, which, in turn, provides the individual with specific goals or purposes to strive towards. According to Eskell-Blokland (in press) an Afrocentric worldview includes a holistic and spiritual unity, with an integrated approach to life and knowledge, and little separation between different aspects of life. A person is perceived as essentially religious with a set of believe systems and practices integrated in every aspect of their whole life. The sacred and secular are both integrated in indigenous beliefs, ceremonies and rituals, and permeate every aspect of a traditional African's life. Eskell-Blokland (in press) describes name giving ceremonies, initiation rites, lobola and marriages, rituals performed at death and burial, prophet's and healers, thwasa, etc., as customs and rituals which can form part of an indigenous perspective on psychology.

Mbiti (1989) says that traditional African beliefs are communal in nature and focus on connecting people to society, and society to the ancestors. According to Eskell-Blokland (in press), individual experiences of the African person are not to be separated from the collective experience which is not restricted to the family and broader community, but also includes the ancestors. African personhood includes social selfhood, ancestor selfhood and spiritual selfhood. According to this African tradition, death can be seen as a part of the cycle of life when a person passes from this world to the world of the ancestors.

Michael Salzman and Michael Halloran (2004) suggest that colonisation brought about deep suffering for indigenous people due to the subsequent destruction of their culture. This is thus a vital source of existential meaning. They further contemplate the human need for meaning in

the context of the consequences of traumatic disruptions of culture and the resultant breakdown of systems of meaning and value for human beings. According to Salzman and Halloran (2004) the traumatic disruption of a people's culture is likely to result in unmanageable anxiety requiring compensatory actions, which may produce destructive consequences.

In Eskell-Blokland's (2001) article, *Falling into the cracks of culture: Counselling at the heart of transformation*, the writer contributed to the discussion on the development of a "dynamic evolutionary indigenous psychology in South Africa in the area of counselling" (p. 1). Eskell-Blokland (2005) refers to falling through the cracks in the culture as the process she identified in psychotherapy where it seemed that clients are "trapped between their traditional belief systems and a modernising, westernising world" (p. 74), for which they were unprepared. She was confronted with the different ways in which different cultures have preferred to explain the problems of the clients, and thus offered different possibilities of dealing with them. She further perceives the challenge to integrate the different perspectives into a framework for the way forward (Eskell-Blokland, 2005).

Eskell-Blokland (in press) furthers this discussion when writing about an indigenous perspective on psychology. She says that local communities who have relied on their cultural traditions to bring meaning in their lives, might experience a possible loss of a sense of identity due to globalisation. Indigenous people may enjoy the benefits of a lifestyle influenced by globalisation, while still needing the emotional comfort and security of their community's traditions. She perceives the process of globalisation (dominated by western ideas), where knowledge is shared across national and continental boundaries, as a potential threat to small local communities by undermining their local traditional cultures.

Yalom (1980) suggests that the Western and non-Western worldviews differ radically in terms of one's attitude towards nature and life. "The contrast then is between a searching-action mode and a harmonising-union one, and often is phrased in terms of doing versus being" (Yalom, 1980, p. 468). Eskell-Blokland (in press) writes that Ubuntu/Botho is one way in which the individual gives expression to the African worldview. According to the Ubuntu philosopher,

Broodryk (2002), Ubuntu is an ancient African worldview which is based on values like humanness, caring, sharing, respect, compassion and associated values ensuring a happy and qualitative human community life in a spirit of family. This *Ubuntu-expression* of a traditional African worldview may contribute to an individual's co-creation of meaningfulness while experiencing an existential crisis because of being HIV positive.

3.3. Existentialism

The literature explores meaning making from an existential perspective and shows that this approach to psychology seems to be relevant for a woman who is in search of meaningfulness and can thus be said to be experiencing an existential vacuum (Frankl, 1965, 1967, 1969, 1978, 1984; May, 1967; Yalom, 1980). The existential approach to meaning is a philosophical one, interested in understanding people's being-in-the world and clarifying what it means to be alive (Van Deurzen-Smith, 1996). According to Pyszczynski, Greenberg and Koole (2004), existential psychology attempts to explain how ordinary humans come to terms with the basic facts of life with which we all must contend.

Pyszczynski et al., (2004) argues that the consideration of existential issues can be found in the work of the great thinkers of the Western classic era, such as Plato and Socrates, and are continued through the work of theologians such as Augustine and Aquinas. Writers such as Dante and Shakespeare also discovered existential issues in the arts and humanities of the European Renaissance. The arts became even more focused on these matters in the romantic period of the 19th century, for example, in the poetry of Keats; the novels of Tolstoy; and the music of Beethoven, Brahms and Tchaikovsky. This issue has become even more dominant in the art since then, for example, in the plays of Beckett, the classical music of Mahler; the rock music of John Lennon; and the surrealist paintings of Ernst, Dali, and many others. "Indeed, the expression of deep existential concerns may be the underlying commonality of all great artistic creation" (Pyszczynski et al., 2004, p. 5).

An explicit, focused consideration of existential issues came to full fruition in the existentialist school of philosophy, which builds on the philosophical line of thought of Descartes, Kant and Hegel, and blossomed in the writings of Kierkegaard, Nietzsche, Heidegger, Sartre, Camus, Buber, Tillich and others (May, 1995). Although approaching existential questions from diverse perspectives and sometimes drawing dramatically different conclusions, all these thinkers addressed the questions of what it means to be a human being, how we relate to the physical and metaphysical world that surrounds us, and how we can find meaning given the realities of life and death (Pyszczynski et al., 2004, p. 5).

According to May (1995), Otto Rank seems to be the first theorist to incorporate existential concepts into a broad theoretical conception of human behaviour, with his theorising of the role of the twin fears of life and death, in the development of a sense of self in the child and the ongoing influence of these forces across lifespan. He anticipated many of the themes to be found in the later existential psychological work, in his analysis of art and creativity, the soul, the fears of life and death, and the will.

Many streams exist in the existential movement and therefore it was not founded by any particular person or group. The existential movement arose spontaneously in different parts of Europe and among different schools of psychology and psychiatry in the 1940s and 1950s. This movement grew out of a war-torn Europe, devastated by destruction and waste, to help people resolve the dilemmas of contemporary life such as isolation, alienation and meaninglessness. Rather than trying to develop sets of rules for therapy, existentialism focused on understanding these deep human experiences (May & Yalom, 1995).

While the fathers of the existential philosophy are Søren Kierkegaard and Martin Heidegger, Victor Frankl was a central figure in developing existentialism (Corey, 2001). Victor Frankl's search for meaning while suffering in the German concentration camps seems to be relevant for other individuals who undergo similar kinds of experiences, although unique in their constructions thereof. Frankl changed his psychoanalytical orientation and reacted against deterministic and behaviouristic notions. It is contended that we are meant to live our lives,

which transcend mere existence and the seeking of power and pleasure. Frankl's central theme is then also the will to meaning. He quotes Nietzsche by saying "He who has a 'why' to live for can bear with almost any 'how'" (as cited in Frankl, 1963, p. 121). He felt that the malady of our time is meaninglessness, or the "existential vacuum", which is often experienced when people do not busy themselves with routine and work. The therapeutic process is aimed at challenging individuals to find meaning and purpose through, among other things, suffering, work and love (Frankl, 1965). Frankl developed logotherapy or "therapy through meaning" (Maddi, 1989).

Rollo May was one of the key figures responsible for bringing over existentialism from Europe to the USA and for translating key concepts into practice. He introduced the textbook *Existence: A new dimension in Psychiatry and Psychology* (May, Angel & Ellenberger, 1958). According to May, it takes courage to "be", and our choices determine the kind of person we become. Together with May, two other important existentialists in the United States are James Bugental and Irvin Yalom. Bugental describes a life-changing approach to live with the essential concern of helping individuals to examine how they have answered life's existential questions and to challenge them to modify their answers to begin living authentically. Yalom has developed an existential approach that focuses on four ultimate human concerns: death, freedom, existential isolation and meaninglessness. In his comprehensive textbook, *Existential Psychotherapy* (1980), which is considered as a pioneering accomplishment, Yalom described existential thought as focused on human confrontation with the essentials of existence (Pyszczynski et al., 2004).

Existentialism can be described as a philosophical approach to psychology that may influence an existential therapist's practice. The philosopher William Barrett (as cited in Pyszczynski et al., 2004, p. 126) defined existentialism as "a philosophy that confronts the human situation to ask what the basic conditions of human existence are and how man can establish his own meaning out of these conditions". It is grounded on the assumption that we are free and responsible for our choices and actions. According to Van Deurzen-Smith (1988), we are the authors of our lives and we ourselves draw up the blueprints for their designs. Individuals are encouraged to reflect on life, to recognise their range of alternatives, and to decide among

them, which to choose. Individuals can recognise that they do not have to remain passive victims of their circumstances, but instead they can consciously become the architects of their lives. Existentialism focuses on issues like alienation, defiance, identity, conflict, human hope and despair (Gould, 1993).

According to Boss (1963), this movement stands for the respect for the person, for exploring new aspects of human behaviour and for divergent methods of understanding people. The current focus of this approach is on individuals who feel alone in the world and are facing the anxiety of this isolation. This is one way that the movement remains relevant for individuals and psychotherapy in the present socio-historical context. The focus is to understand deep human experiences and how we continually re-create ourselves through initiating and participating in different projects. Humans are in a constant state of transition: emerging, evolving and becoming. According to the existential theory, being a person implies that we are discovering and making sense of our existence. We are thus continually questioning ourselves, others and the world around us. The specific questions we ask vary in accordance with our developmental stage in life, but the fundamental themes stay the same. We all ask the questions: Who am I? Who have I been? Where am I going? (Van Deurzen-Smith, 1988).

Existential psychologists speculate about the human confrontation with very abstract questions regarding the nature of existence and the meaning of life (Pyszczynski et al., 2004):

When we look for answers to the questions we have been discussing, we find, curiously enough, that every answer seems to somehow impoverish the problem.... The only way of resolving - in contrast to solving - the question is to transform them by means of deeper and wider dimensions of consciousness. The problems must be embraced in their full meaning, the antinomies resolved even with their contradictions. (May, 1969, pp. 307-308)

According to Corey (2001), propositions of existentialism on the basic dimensions of the human condition include the propositions of the capacity of a sense of self-awareness, freedom and responsibility, establishing of relationships, values, the search for meaning, anxiety and an

awareness of death and non-being. Maddi (1989) includes *being-in-the-world* as a core characteristic of existentialist thought. Goldstein (2004) and Schwär (2001) suggest that the notion of a Higher Being is an important value of existentialism.

3.3.1. *Being-in-the-world*

According to Binswanger (1963), *being-in-the-world* is a core characteristic intended to emphasise the unity of a person and environment.

The emphasis is not merely one of interaction between the person and his or her environment; rather, person and environment are essentially one and the same. This is because both being and world are human creations, so interdependent as to be inseparable. (Maddi, 1989, p. 140)

Being is a verb form, a participle, implying an active and dynamic process. Existence does not occur just within the individual, but rather between individuals and their world (Boss, 1963). The concept *world* emphasises the environment that persons create for themselves through exercising their capacities to produce being and the expression of that being in action. In order to understand a person's existence, one must appreciate the manner in which being and world merge. "World is the structure of meaningful relationships in which a person exists and in the design of which he participates" (May et al., 1958, p. 59).

Existentialists (Binswanger, 1963; Frankl, 1969; May et al., 1958) make the distinction between three modes of being-in-the world: *Umwelt*, *Mitwelt* and *Eigenwelt*. *Umwelt* refers to the biological and physical world around one and concerns one's construction of the biological and physical tie between oneself and the world. The *Mitwelt* (with-world) refers to one's perceptions of and orientations toward one's interaction with others as well as social institutions. *Eigenwelt* means own-world, and refers to the internal dialogue of relationship to oneself. All three modes assume an awareness of one's *Umwelt*, *Mitwelt* and *Eigenwelt*, which are a unity (Maddi, 1989).

3.3.2. Capacity for a sense of self-awareness

According to Existentialism, human beings can reflect and make choices because they are capable of a sense of self-awareness. To increase a sense of self-awareness is to increase our capacity to live fully and to create greater freedom. We can choose whether we want to restrict or expand our consciousness. The expansion of our sense of self-awareness is fundamental for human growth because it is at the root of most other human capacities. Increasing a sense of self-awareness includes awareness of alternatives, motivations, and factors influencing the person and personal goals. Once we become conscious beings, we are aware that inherent existence is a necessity-to-act (May et al., 1958).

Existentialists are of the opinion that abnormal behaviour results from the conflicts between people's essential nature and the demands that they or others make on them. "The more alienated a person becomes from his or her total being, the fewer alternatives are available, behaviour becomes increasingly stereotyped, inhibited, conforming, and morally rigid" (Sue, Sue & Sue, 1994, p. 62).

According to the theologian Paul Tillich (1952), there are certain conditions inherent in existences that tempt us to run from too much awareness. These conditions fill us with dread, which he calls *existential anxiety*. The first source of anxiety comes with our acute awareness that at some unknown time we must die. Being implies non-being. Our most significant others can also die, ending not only their existence but also part of our being that was intimately connected with them. There is thus a price to pay for increased awareness. Corey (2001) contends that, "Ignorance of our condition may have brought contentment along with a feeling of partial deadness, but as we open the doors in our world, we can expect more struggle as well as the potential for fulfilment" (p. 147).

3.3.3. *Freedom and responsibility*

An existential theme is that people are free to choose among alternatives and therefore play a large role in shaping their own destinies. "Even though we have no choice about being thrust into the world, the manner in which we live and what we become are the result of our choices" (Corey, 2001, p. 147). May (1967) defines freedom as "the individual's capacity to know that he is the determined one, to pause between stimulus and response and thus to throw his weight, however slight it may be, on the side of one particular response among several possible ones" (p. 175). According to Frankl (1978), the freedom of the will, which is a decision that needs to be taken, is for the unbiased person a matter of course and will result in the immediate experience of herself as being free.

From an existentialist point of view, individuals need to use existing freedom but also need to take into account that it includes responsibility. According to May (1967) responsibility means, "I cannot become a self except as I engage continuously in responding to the world of which I am part" (p. 175). The existentialist philosopher Jean-Paul Sartre calls for a commitment to accept responsibility for directing our own lives and to choose for ourselves. "Freedom is only initiated once boundaries have been explored" (as cited in Van Deurzen-Smith, 1988, p. 20).

Living authentically implies being true to our own evaluation of what is a valuable existence for us. We experience existential guilt if we do not live authentically and are aware of an evaded commitment, or having chosen not to choose. Assuming responsibility is thus a basic condition for change. Frankl (1978) links freedom with responsibility and suggests that a Statue of Responsibility (on the West Coast) complements the Statue of Liberty on the East Coast. We are consequently not free from restrictions, but we are free to take a stand against these restrictions.

3.3.4. *Establishing meaningful relationships*

According to Corey (2001)

People are concerned about preserving their own uniqueness and centeredness, and at the same time they have an interest in going outside of themselves to relate to other beings and nature. Each of us would like to discover a [sense of] self – that is to find (or create) our personal identity. (p. 148)

Farha (1994) writes that some persons become trapped in a "doing mode" to avoid the experience of "being". According to Tillich (1952), it takes courage to learn to live from the inside. We struggle to discover, to create and to maintain the core deep within our being.

The human condition can be described with the paradox that humans are existentially both alone and related (May, 1967). Existentialists postulate that part of the human condition is the experience of aloneness. A sense of isolation arises when we recognise that we cannot depend on anyone else for our own confirmation. We alone must give a sense of meaning to life and need to decide how we will live. Ultimately, however, we are alone. According to Bugental (1965), our isolation, our fundamental aloneness in the universe, is a condition. Regardless of how intimate I am with others, I can never be them, nor they me. We share experiences, but we are always under the threat of never totally understanding each other.

Corey (2001) states that humans depend on relationships with others. "We want to be significant in others' world, and we want to feel that others' presence is important in our world" (p. 149). Existentialists distinguish between a neurotically dependent attachment between persons and a life-affirming relationship in which both persons are enhanced and where therapeutic, healthy and mature relationships develop.

When we-are-with-others, we know that they are conscious beings who can reflect upon us, something which makes it possible for us to be on the level of existence called, being-for-others. Frankl (1969) comments that a sense of meaning is not simply innate, rather one finds this

meaning through a commitment to something that is beyond oneself. Meaning is found in relation to others and in transcending a sense of self.

3.3.5. Values

According to Schwär (2001), Frankl very often uses the concepts *meaning* and *values* interchangeably. Frankl (1969) points out that meaning in life can be found in three principal ways: the creative things we do, the uplifting things we experience, and the kind of attitude we have towards inevitable suffering. The *creative values* we experience are those creative contributions to life, which make us to feel meaningfully part of life. When work, for example, is a creative expression of responsibility, we find meaning in our work (Shantall, 1997).

Experiential values are a blessing we receive of life and are manifested in what is good, beautiful, genuine and true. For Frankl, the greatest experiential value is love, which brings us in vital touch with others and ourselves. According to Frankl (1959), a fulfilled human being wants to be challenged and transcends her sense of self to courses outside herself and her own agenda. She wants to be faced with a task and to feel that there is a calling for her in life, which can make it possible for her to dedicate herself to construing values and ideals. Frankl perceives a sense of self-transcendence as an integral part of becoming more authentic. For Frankl, too much focus on a sense of self may ultimately inhibit psychological health. When moving beyond their sense of self, while in the process of searching for meaning, human beings might experience enthusiasm, inspiration and joy (Shantall, 1997).

We experience *attitudinal values* through the right attitudes we have towards life, especially towards inescapable suffering. According to Frankl (1967), there are three inevitable facts confronting us all the time, namely pain, guilt and death, which he calls, "the tragic triad of human existence" (p. 87). He concurs, "To live is to suffer, to find meaning in life is to find meaning in suffering. If there is a purpose in life at all, there must be a purpose in suffering and dying" (Frankl, 1959, p. x). If a situation cannot be changed, if suffering cannot be avoided,

what is engaged in is the freedom to change ourselves (Frankl, 1978). Frankl (1959) believes that by choosing your attitude in any given set of circumstances you choose your own way.

3.3.6. *Search for meaning*

Shantall (1997) writes that

by *meaning* Frankl meant the opportunity, the task or duty presented to and discerned by us through our conscience as something we are to realise or grasp in each and every unique situation of our own personal lives. Every situation of life contains a unique challenge to live our lives purposefully, with meaning. (p. 531)

Frankl and Yalom (1980) agree that meaning must be pursued obliquely and is not something we can directly search for and obtain. Finding meaning is a by-product of engagement, which is a commitment to creating, loving, working and building. Redekopp (1990) defines meaning as "...the sensibility of the human existence..." (p. 16) and describes it as "a concept held by an individual that requires a belief in something, an understanding of something, commitment to something and a relationship to something" (p. 17).

A distinctly human characteristic is the struggle for a sense of purpose and significance in life. A person might experience a vacuum if she discards traditional (and imposed) values without finding other, suitable ones to replace them. They may feel like a boat without a rudder and need to create new guidelines as well as a value system that are appropriate for the newly discovered facets of their sense of self. A person can create an internally derived value system that is consistent with her way of being and provides a meaningful life (May, 1967).

A person might face the prospect of her own mortality when the world she lives in seems meaningless, and she may wonder whether it is worth it to continue struggling or even living. Yalom (1980) notes that the crisis of meaninglessness "stems from the dilemma of a meaning-seeking creature who is thrown into a universe that has no meaning" (p. 9). For Frankl (1978)

such a feeling of meaninglessness is the major existential neurosis of modern life. He calls meaninglessness in life that leads to hollowness and emptiness, the *existential vacuum*. Frankl (1967) refers to an existential vacuum as a state where people lack any noteworthy sense of meaning, motivation or direction in life and experience a sense of inner emptiness and aimlessness. According to Shantall (1997), this condition can result in various pathological states, especially in a lack of personal authenticity, where superficial conformity replaces internalised personal convictions.

Because there is no pre-ordained design for living, Corey (2001) notes that people are faced with the task of creating their own meaning as part of a meaningful life when they experience meaninglessness. Existentialists relate the concepts *existential guilt* and *meaninglessness* with each other and describe existential guilt as "a condition that grows out of a sense of incompleteness, or a realisation that we are not what we might have become. It is an awareness that our actions and choices express less than our full range as person" (Corey, 2001, p. 151). Frankl (1978) contends that people who confront pain, guilt, despair and death can challenge their despair and thus triumph. Psychological literature suggests that the creation of meaning enhances mental health, advances a sense of self-actualisation, enhances one's ability to cope with stress and initiates a sense of *self-transcendence* (Goldstein, 2004).

3.3.7. *Anxiety as condition for living*

Anxiety needs to be confronted as an inevitable part of the human condition. Existentialists differentiate between normal and neurotic anxiety (May, 1967). *Normal anxiety* is an appropriate response to an event being faced, does not have to be repressed and can be used as a motivation to change. They see *existential anxiety* as a constructive form of normal anxiety and a potential source of growth. We experience existential anxiety as we become increasingly aware of our freedom and the consequences of accepting or rejecting that freedom. The anxiety accompanying the reconstruction of our lives can be a signal that we are ready for personal change and can help us to dare to take the steps necessary to change the direction of

our lives. According to May (1981), freedom and anxiety are sides of the same coin. Anxiety is associated with the excitement in the birth of a new idea.

May (1967) continues by stating that *neurotic anxiety* is out of proportion to the situation, typically out of awareness and it tends to immobilise a person. To be psychologically healthy entails living with as little neurotic anxiety as possible, while accepting struggle with normal anxiety as a part of living. Anxiety from an existential viewpoint can be seen as a stimulus for growth – life cannot be lived, nor can death be faced, without anxiety (May & Yalom, 1995). A person who has the courage to face her sense of self is, nonetheless, frightened. Opening up to new life thus means opening up to anxiety (Corey, 2001).

One of the aims of existential therapy is to help clients to come to terms with the apparent paradoxes of existence, for example, certainty and doubt (May, 1967). As people recognise the realities of their confrontation with pain and suffering, their need to struggle for survival, and their basic fallibility, they experience anxiety. Van Deurzen-Smith (1991) contends that

we need to question and scrape away at the easy answers and expose ourselves to some of the anxiety that can bring us back to life in a real and deep way, otherwise it would be similar to cutting off a source of vitality. (p. 46)

To learn how to have a sense of living without props can be a necessary phase in life's journey from dependency to autonomy.

3.3.8. *Awareness of death and non-being*

Death is not viewed negatively, but rather holds awareness thereof as a basic human condition that gives significance to living (Yalom, 1980). According to existentialists, it is a distinguished human characteristic and ability to grasp the reality of the future and the inevitability of death simultaneously. This recognition helps us to live a more authentic life (Boss, 1963). Life becomes insipid and meaningless if we try to defend ourselves against the reality of our

eventual death, but if we realise that we are mortal, we know that each moment is crucial. Our awareness of death is the source of zest for life and creativity. Death and life are interdependent, and though physical death destroys us, the idea of death also saves us (Yalom, 1980). Those who fear death ultimately also fear life.

According to Shantall (1997), Frankl has made a unique contribution in the field of optimal development because of his view that mature people have accepted the tragic faculties of life, and have done so in a way that, far from diminishing their joy in life, their belief in the meaning of life is actually deepened. Frankl (1959) notes that people who discover meaning in suffering have reached the highest peak of development. He regards himself as a personal witness to the fact that meaning can be found in suffering, guilt and death. Death for Frankl is the boundary which makes life a unique, unrepeatable opportunity. He believes that life is given to us so that we can find meaning, even if it is in suffering. Non-being is the ground against which the figure of being is created (Yalom, 1980).

3.3.9. *Sense of a Higher Being*

Shantall (1997) notes that Frankl describes the spiritual dimension as the “personal ground of being” (p. 535). According to Frankl (1969), people obtain meaning through active pursuit. Individuals need not only seek meaning in a responsible manner but are also making decisions regarding meaning under the guidance of the conscience. According to Schwär (2001), the conscience has an intuitive nature, which allows God's wishes to become known through mutual communication. Frankl (1969) views the conscience as greater than the individual, as the conscience communicates with a Higher Being. He perceives conscience as the ability to discover meanings where others are unable to do so. Schwär (2001) contends that the search for meaning is a dialogue with a Higher Being and thus has a distinctive religious character. The meaningful properties of religion depend on the content of one's beliefs as well as one's spiritual orientation towards a specific creed. "A religious orientation therefore only becomes meaningful if it is authentic and internalised" (Schwär, 2001, p. 2).

When speaking about religion, Frankl (1969) refers to the spiritual dimension of humanity or of the noölogical aspect of an individual's life. According to Goldstein (2004), Frankl uses the concept of religion in its widest sense possible and does not merely refer to traditional religions and God. He describes how religious beliefs are formed by both universal and idiosyncratic values. Schwär (2001) notes that the content of one's religious belief is based on particular values that involve universal (societal) and unique (idiosyncratic) qualities. Universal values constitute specific belief systems held by a community or a particular culture that a person can follow in order to live a meaningful life.

Schwär (2001) investigates whether African people can find existential meaning in situations where their traditional values no longer exist. He says that Frankl believes that socio-cultural changes occurring over time, may change universal values and thrust a person into a state of meaninglessness. According to Schwär (2001), this situation may be seen to have occurred throughout the previous century in South Africa where rural black people were exposed for decades to the influence of Western values and norms. He conjoins with Mbiti (1989) when he states that although many modern black people have managed to integrate Western beliefs meaningfully into their existing worldview (acculturation), social change is threatening to alienate black people from their spiritual traditions. Mbiti (1989) is of the opinion that black people's beliefs are being eroded and that by living between two worlds, high levels of meaninglessness are experienced increasingly. Frankl (1959), however, argues that one can still obtain meaning through unique values, despite the apparent erosion of societal values.

According to Frankl (1959) unique values are individually found through the guidance of the conscience, which are not tied to any specific ideology. These unique values are able to provide direction to a person's life under all circumstances. These absolute values are religious in nature as they are discovered through the conscience, which adhere to God's wishes. "They enable a person to find a divine purpose irrespective of the vicissitudes of life or of changes in the *Zeitgeist*" (Schwär, 2001, p. 3). According to Schwär (2001), this would imply that although black Africans might have lost touch with their traditional spiritual roots, they would still be able

to find meaning via unique values. Gould (1993) writes that theorists dispute the means of finding meaning, but agree that each individual is a bearer of values and has the freedom of choice - motivated by a will to meaning. Schwär (2001) notes that the African worldview has a deeply religious character and thereby answers questions of meaning. Although individuals may be spiritually deculturated, it is still possible for them to authentically embrace and fully integrate the belief system of a foreign culture. "Although such persons do not find meaning in their own cultural values, they might create a purpose in life by fully internalising the creed of another society" (Schwär, 2001, p. 3).

3.4. Existentialism and HIV/AIDS

Literature examines the social constructions that shape and guide the personal experience of the HIV disease (Dansky, 1994; Sontag, 1991). It explores the intersection and influence of culture, gender and politics on the experience of living with HIV/AIDS. Bruner (1990) focuses on meaning and the processes involved in the construction of meanings. He argues that in order to gain insight into an individual, one must first understand how her experiences and behaviour are governed by her meaning making.

According to Existentialism, people living with HIV/AIDS are able to choose how to respond to their illness, because they are equipped with the capacity to perceive themselves as both subject and object, as a being to which things happen (May, 1967). One's will to meaning, and meaning in suffering, become evident as people living with HIV/AIDS struggle to make sense of life. The pursuit of meaning becomes more than an inalienable right but rather the very essence of their humanness (Fabry, 1968).

In the case of HIV/AIDS, where one's entire sense of self and being-in-the-world is questioned, one becomes aware of an existential crisis, focussing specifically on issues of alienation, defiance, identity, conflict, human hope and despair (Gould, 1993). The awareness of one's mortality and the fragility of life deeply affect the lives of people living with HIV/AIDS. Thus, by

the very nature of their imminent mortality, people living with HIV/AIDS are driven to find meaning and significance in their existence.

Psychological experiences of a person living with HIV/AIDS, for example, fear, loss, grief, guilt, denial, anger, anxiety and depression, may result in feelings of meaninglessness. The impact of the HIV infection on significant others as well as anticipated and real socio-economic difficulties, may implicate that a person living with HIV might experience hopelessness (Van Dyk, 2005).

People living with HIV/AIDS need to find meaning in their illness. Response needs to be a response through action. Taking action, such as making desired life changes, starting a relationship, exerting control over medical decisions, becoming politically active, or developing a spiritual practice, has helped many people who live with HIV/AIDS to develop and maintain a sense of hope. Participating in support groups have been found to be effective in helping people who live with HIV/AIDS to initiate, mobilise and achieve personal, family and political goals (Goldstein, 2004).

According to Frankl (1967), one is not only responsible towards oneself and others in fulfilling meaning, but also to a Higher Being. Wood and Aull (1990) notes that spirituality, beliefs and maintaining hope have been found to be positively associated with the ability to live effectively with HIV/AIDS. Gould (1993) says that the existential inquiry into HIV/AIDS examines what it means to be alive and the search for meaning becomes a search for a sense of wholeness.

3.5. Conclusions

It becomes apparent that multiple descriptions, understandings and conceptualisations of the meaning of life exist. Existentialists agree that there is no meaning in life that categorically exists and which is a blueprint for all human beings to obtain. Each human being needs to search for and construct her own meaning through her unique existential experiences. Meaning

in life cannot be created by only searching inwardly but is created by transcending a sense of self, giving to others as well as to live for a cause outside the sense of self. In the case of a woman who needs to live with HIV/AIDS, the paradox is apparent: how to construct meaning and life, in the foresight of death. Propositions of Existentialism were constructed by philosophers/psychologists who struggled with meaninglessness in their own lives and had to search and create meaningfulness for themselves. The next chapter discusses the methodology, which was followed in order to do the research. The researcher's ethical values and considerations are also included in chapter 4.

CHAPTER 4: METHODOLOGY AND ETHICAL CONSIDERATIONS

4.1. Introduction

In this research, the kind of information required and the analytic strategy to be followed is *qualitative*. According to Struwig and Stead (2001), the term qualitative research does not describe a single research method. Writers (Creswell, 1998; Denzin & Lincoln, 2000; Struwig & Stead, 2001) agree that one undertakes qualitative research in a natural setting where the researcher is an instrument of data collection: someone who gathers words or pictures, analyses them inductively, focuses on the meaning of participants, and describes a process that is expressive and persuasive in language. Creswell (1998) defines qualitative research as

an inquiry process of understanding based on distinct methodology traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analysis words, reports detailed views of informants, and conducts the study in a natural way. (p. 14)

Stake (1995) remarks that the epistemology of qualitative research is existential (non-deterministic) and constructivist. Qualitative research tries to establish an empathic understanding for the reader, through thick description, conveying to the reader what experience itself would convey. "The function of research is not necessarily to map and conquer the world but to sophisticate the beholding of it" (Stake, 1995, p. 43). Thick description, experiential understanding and multiple realities are expected in qualitative case studies. Research requires looking at a wide domain of contexts: temporal and spatial, historical, political, economic, cultural, social and personal (Stake, 2000).

The researcher strove for coherence and sequence in order to fit various elements of the design together within the research paradigm. The aim was to produce findings that are convincing (Durrheim & Wassenaar, 2004). The researcher uses theory *triangulation* in order to clarify meaning by identifying different ways in which the phenomenon can be viewed. Stake (2000) acknowledges that no observations or interpretations are perfectly repeatable and defines

triangulation as "a process of using multiple perceptions to clarify meaning and verifying the repeatability of an observation or interpretation" (p. 443). He therefore notes that the role of the qualitative researcher is to emphasise episodes of nuance, the sequence of happenings in context and the wholeness of the individual. "The qualitative case researcher tries to preserve the multiple realities, the different and even contradictory views of what is happening" (Stake, 1995, p. 12).

Although each individual is perceived to create her own unique meaning system, the findings will be *transferable* in terms of helping to try to understand other contexts or groups similar to those studied. This researcher aimed to focus on a process in order to obtain an in-depth perspective on the case (Creswell, 1998). Research findings needed to be transferable by producing detailed and rich descriptions of the contexts. Stake (2000) describes the importance of transferability and notes, "A new case cannot be but some combination of cases already known. A new case without commonality cannot be understood. Yet a new case without distinction will not be noticed" (p. 443).

Detailed accounts of the structures of meaning that develop in the specific context were obtained. The understandings may be transferred to new contexts in other studies and might provide a framework with which to reflect on the unique arrangements of meaning and action that occur in these new contexts. This qualitative study aimed to be *dependable*, which was intended to be achieving through the rich and detailed descriptions that show how actions and opinions are rooted in and develop out of contextual interaction (Durrheim & Wassenaar, 2004).

Because of the sensitivity of the research topic and the existential experiences of the participant, the researcher agrees with Kelly (2004b) by acknowledging the importance to communicate interpersonal skills, especially the abilities to build and maintain rapport, to make the participant feel relaxed and unguarded, to be open and forthright, to tolerate ambiguity and contradiction, and not to be thrown by confusion and apparent chaos. "The interpretative researcher is often in the position of being a facilitator, and the fruitfulness of the enquiry is a product of the skill of the researcher in engaging creatively with participants and contexts" (p.

396). The researcher believes in the principle of relativity, which means that each researcher contributes uniquely to the study of a case and derives her personal meanings. These and other differences are relative to the purposes of the study, the immediate situation of the case and the circumstances of the reader (Stake, 1995).

The role of an interpreter and gatherer of interpretations seems to be central to a case researcher. Most qualitative researchers nourish the belief that knowledge is constructed rather than discovered (Kvale, 1996). The world we know is indeed a particular human construction.

Infants, children, and adults construct their understandings from experience and from being told what the world is, not by discovering it whirling there untouched by experience. What they know of reality is only what they have come to believe, not what they have verified outside their experience. (Stake, 1995, p. 100)

4.2. Sampling

An information-rich case has been pre-selected for this study. According to Stake (2000), the case is a specific, complex, functioning and integrated system whose behaviour is patterned. The researcher ensured that the participant has met the requirements for the characteristics of a respondent, as stated by Kelly. Kelly (2004b) contends that the participant needs to have the ability to describe personal experiences of what is researched, have good communicative skills (ability to describe experience in detail), openness and undefensiveness as well as an interest in participating and the perception that it may in some way be of value to participate.

According to Lindegger (2004), case studies are intensive investigations of particular individuals and are defined as "ideographic research methods, that is, methods that study individuals as individuals rather than as members of a population" (p. 255). These methods are used to learn enough about a case to encapsulate complex meanings in descriptive narrative so that readers can vicariously experience these happenings and draw their own conclusions. Stake (2000), on the other hand, notes "As a form of research, case study is defined by interest in individual

cases, not by the methods of inquiry used" (p. 435). Case study is thus not a methodological choice but rather a choice of what is to be studied. According to Stake (2000, p. 436), "A case study is both a process of inquiry about the case and the product of that inquiry". This research focuses on a single individual who is experiencing an existential crisis and needs to construct meaning while living with HIV/AIDS, within the context in which she exists. The interest of the participant is defining the case and the case is both the process as well as the product of inquiry.

An intrinsic case study is undertaken "because, first and last, the researcher wants better understanding of this particular case" (Stake, 2000, p. 437). Yin (1994) has advanced the epistemology of the particular and contends that a case is being studied when it itself is of special interest. The real business of case study is particularisation, not generalisation. The emphasis is on uniqueness and on understanding the case itself. We take a particular case and come to know it well. The research aims the inquiry towards a understanding of what is important about the participant within her own world and is perceived to be her own issues, contexts, interpretations and her thick description.

The research is intensive with a single individual and descriptive in nature, as it planned to provide rich information about the participant. It has the advantage of allowing new ideas and suggestions to emerge from careful and detailed observation. "Case studies often generate hypotheses that might be more rigorously tested by other research methods" (Pillay, 2004, p. 256). According to Stake (1995), "Case study research is not sampling research. We do not study a case study primarily to understand other cases. Our first obligation is to understand this one case" (p. 4). The case is expected to represent some population of cases in order to gain the best possible explanations of the phenomena. We examine the case that we feel we can learn the most from. "Potential for learning is a different and sometimes superior criterion to representative-ness" (Stake, 2000, p. 446).

Creswell (1998) recommends that a single individual may be the case "when the researcher can obtain substantial contextual material about the individual..." (p. 66). Kvale (1996) notes that

the purpose of a single case study is to understand the world as experienced by one specific person. This one subject is sufficient. According to Stake (1995), a "Case study is the study of the particularity and complexity of a single case, coming to understand its activity within important circumstances" (p. 14). With its own unique history, the case is a complex entity operating within a number of contexts. Yin (1994) describes a case study as an exploration of a bounded system over time through detailed, in-depth data collection involving multiple sources of rich information in context.

4.3. Methods of data collection

Data was obtained from one-to-one, *semi-structured interviews* (Appendix A) and took the form of language. The interview form used is a semi-structured interview for:

It has a sequence of themes to be covered, as well as suggested questions. Yet at the same time there is an openness to changes of sequence and forms of questions in order to follow up the answers given and the stories told by the subjects. (Kvale, 1996, p. 124)

The researcher was the primary instrument for both collecting and analysing the data. This method permitted rich and detailed information of the case and allowed the researcher to build up an understanding of the phenomena through conversing about particular instances of the phenomena as they emerged in specific contexts. The particular information was categorised into themes from where a more general picture of the phenomenon was built from particulars (Kvale, 1996).

Conducting an interview with the participant was a more natural form of interacting and it provided both the opportunity to interrelate with each other while the participant was sharing her experiences. Terre Blanche and Kelly (2004) perceive interviews as simply conversations, but at the same time also as highly skilled performances. Kvale (1996) notes that the qualitative research interview attempts to understand the world from the subject's points of view, to unfold

the meaning of people's experiences and to uncover their lived world prior to scientific explanations. According to Kvale (1996), an interview is an interchange of views between two people, conversing about a theme of mutual interests. The knowledge created by the interview is interrelational: "If you want to know how people understand their world and their life, why not talk with them?" (Kvale, 1996, p. 1).

The interviews were semi-structured in order to create a space within which the participant could feel at ease to talk in-depth about her feelings and experiences. "Qualitative researchers take pride in discovering and portraying the multiple views of the case. The interview is the main road to multiple realities" (Stake, 1995, p. 640). The interviews were tape-recorded in the context of a consulting room where privacy was respected. "The meaning of what is being said in an interview can usually only be interpreted in the context of the sentences that surround it and the conversation as a whole" (Terre Blanche & Kelly, 2004, p. 132).

The participant was given a summary of what the interviews were all about, two days before the interviews took place (Appendix A). She had the opportunity to reflect on the questions prior to the actual interview sessions. The type of interview questions in the pre-view were mainly introducing, follow-up, probing and interpreting questions (Kvale, 1996). Trust was already established through the therapeutic process and the researcher had pre-knowledge of the participant's journey.

Open-ended questions were used right at the start of the interview, providing very little further structuring during the rest of the interview. "Such opening questions may yield spontaneous, rich, descriptions where the subjects themselves provide what they experience as the main dimensions of the phenomena investigated" (Kvale, 1996, p. 133). The participant could converse about her journey in a spontaneous way. The researcher used only a few questions during the interview; mostly to clarify what the participant meant. The participant addressed the questions, which were given to her prior to the interviews according to her preferences and needs. Process notes were kept throughout the four interviews as well as thereafter and can be

conceptualised as descriptive and reflective notes (Creswell, 1998). The four interviews lasted between 45 and 60 minutes each.

The interviews were transcribed, the transcriptions given to the participant who agreed that the content of the information is congruent to what she meant to say. These transcriptions were later analysed, interpreted and described. Kvale (1996) contends that transcripts are, however, artificial constructions from an oral to a written mode of communication.

Transcribing involves translating from an oral language, with its own set of rules to a written language with another set of rules. Transcripts are not copies or representations of some original reality, they are constructions that are useful tools for given purposes".
(p. 165)

4.4. Data analysis

4.4.1. Analysis

According to Terre Blanche (2004), the principle of interpretative analysis needs to be respected, namely to stay close to the data and to interpret it from a position of empathic understanding. Terre Blanche (2004) refers to the anthropologist Clifford Geertz (1973), when stating that

the purpose of interpretative analysis is to provide 'thick description', by which is meant thorough description of the characteristic, processes, transactions and contexts that constitute the phenomenon being studied, couched in language not alien to the phenomenon, as well as an account of the researcher's role in constructing this description. (p.139)

The type of data analysis is holistic in nature (Yin, 1994). The researcher analysed the entire case and presented descriptions, themes and interpretations related to the case as a whole (Creswell, 1998).

4.4.2. *Steps in data analysis*

The researcher's data analysis involved: reading through the data repeatedly, breaking the data up by thematisation and categorisation, and then building the data up in novel ways through elaboration and interpretation (Kvale, 1996). The steps of familiarisation and immersion, inducing themes, coding, elaboration as well as interpretation, have been followed (Terre Blanche & Kelly, 2004).

4.4.2.1. Familiarisation and immersion

This step involved the development of ideas and theories about the phenomenon being studied. According to Terre Blanche and Kelly (2004), "Data gathering in interpretative research is not just a mindless exercise, but involves development of ideas and theories about phenomenon being studied, even as the researcher makes contact with gatekeepers and sets up interviews" (p. 141). At this stage, the researcher had a preliminary understanding of the meaning of the data and needed to immerse in it again, this time working with texts (interview transcripts) rather than with lived reality.

4.4.2.2. Inducing themes

According to Terre Blanche and Kelly (2004), this step involves moving beyond merely summarising the content towards processes, functions, tensions and contradictions. An optimal level of complexity was found as well as different kinds of themes (and sub-themes) covering a broad array of issues. An existential philosophical point of view was used to identify themes as indicated in Appendix B. The identified themes were derived from the transcriptions and process notes. Relevant direct quotes, which reflect issues and themes, in the participant's own words are cited as part of the thick description in chapter 5.

4.4.2.3. Coding

This step included breaking data up in analytically relevant ways. Data was coded - this entails marking different sections of the data as being instances of, or relevant to, one or more of the themes. A text domain (body of data) has been broken down in labelled, meaningful pieces. Bits of coded material have been clustered together under the code heading and has further been analysed as a cluster in relationship with other clusters (Terre Blanche & Kelly, 2004).

4.4.2.4. Elaboration

This step involved exploring themes more closely in order to capture the finer nuances of meaning.

4.4.2.5. Interpretation

In the final step the researcher's interpretation has been put together through a written account of the phenomenon studied, using thematic categories from the analysis as sub-headings. A thick description of the themes derived from the interviews, integrated with propositions of existentialism within the context, is given and reflected upon in chapter 5.

4.5. Ethical considerations

According to Stake (2000), "Qualitative researchers are guests in the private spaces of the world. Their manners should be good and their code of ethics strict" (p. 447). The researcher respects the autonomy of the participant in the research. The researcher addressed issues of the voluntary and informed consent of the research participant, her freedom to withdraw from the research at any time and the participant's right to autonomy in any publication that might

arise out of the research (Kvale, 1996). Although the participant already orally agreed to participate in the research process, she has confirmed informed consent, by signing a letter of consent (Appendix C). Debriefing after the completion of the study has taken place in order to recognise the autonomy and dignity of the participant (Durrheim & Wassenaar, 2004).

The principle of non-maleficence was also respected. The research aimed at doing no harm to the research participant or to any other person or group of persons. According to Stake (2000), "Risks to well-being cannot be inventoried but should be exemplified" (p. 439). Potential risks that the research may inflict namely physical, emotional, social or other forms of harm on any person or creature involved in the study were considered. The principle of beneficence was respected, as the research was designed so that it could benefit the research participant, other researchers and society at large (Kvale, 1996).

The participant was assured of the parameters of confidentiality of information supplied by her. The intended format of publication, namely an academic study, was specified. The participant was also informed about how the data was recorded, stored and processed for release. The researcher asked the participant for information that is central to the study and thereby reduces the inadvertent disclosure of confidential information. Results are reported whilst bearing the rights of the participant in mind. No falsification or fabrication of data was allowed and the limitation of the researcher's findings was communicated (Struwig & Stead, 2001).

A sensitive topic is addressed. Because of the already existing confidential therapeutic relationship this could pose a personal risk for the participant as well as a contextual risk. "If the interview topics involve strongly personal and emotional issues, they may in some cases bring forth deeper personal problems requiring therapeutic assistance" (Kvale, 1996, p. 155). The researcher intended to be especially cautious in areas of deep personal experiences where thoughts and experiences were disclosed (Kelly, 2004a). The participant had insight into the type of questions she was going to be asked. Ethically problematic territory might occur because the outcome of the research may lead to reflexivity (change in the situation) and therefore the participant has the option to go for therapy if she needs to (Kvale, 1996).

The researcher and the participant represent multi-cultural perspectives and realities. Therefore the study is conducted in an "inter-cultural fashion" (Eskell-Blokland, 2005, p. 147). Vontress and Epp (1999) discuss the existential foundation of cross-cultural counselling. Because the existential approach is grounded in the universal characteristics of human beings, they maintain that it is perhaps the most applicable of all approaches when working with culturally diverse individuals. They write: "existential counselling is probably the most useful approach to helping clients of all cultures find meaning and harmony in their lives, because it focuses on the sober issues each of us must inevitably face: love, anxiety, suffering, and death" (p. 32).

According to Corey (2001), these are the human experiences that transcend the boundaries that separate cultures. In this sense one can say that there is an element of universality present (Yalom, 1995). Because of this the researcher needs to have a cultural sensitivity and tolerant philosophical outlook that will fit all cultures.

4.6. Conclusions

The nature of this research is qualitative. An in-depth analysis of a single individual case is the object of investigation and the unit of analysis. Data has been collected in the form of spoken language through recorded interviews, which were transcribed, analysed and interpreted. The researcher's data analysis involved reading through the data repeatedly, breaking the data down by thematising and categorising them, and building the data up in novel ways through the process of elaborating and interpreting. The steps of familiarisation and immersion, inducing themes, coding, elaboration as well as interpretation have been followed. Chapter 5 describes the researcher's interpretation of the themes derived from the interviews with the participant.

CHAPTER 5: THICK DESCRIPTION OF PARTICIPANT'S EXPERIENCES

5.1. Thick integrative description of themes derived from participant's experiences of living with and making meaning of HIV/AIDS

5.1.1. Introduction

This chapter introduces the participant through extracts from her interviews and attempts to explore and analyse the main themes and experiences that she has of living with and making meaning of HIV/AIDS. It presents an analysis of the participant's interviews in an attempt to gain an in-depth understanding and insight into the phenomenon under investigation. The themes are derived from the content of the transcriptions and are conceptualised according to existentialism. Although themes are mainly derived from the interviews and transcriptions thereof, some relevant referrals to the therapeutic process are also made. Citations are quoted in order to language the participant's experiences of reality in the specific time and space in which the interviews took place. The citations remain the words of the participant herself. Clarifications are added in brackets in cases where the researcher finds the inclusion thereof essential for contributing to the participant's description of her experiences and context. Pseudonyms were used to protect the identity of the participant and her significant others.

The following is a thick description of the researcher's interpretation of the participant's experiences of living with HIV/AIDS and the meaning making thereof. An integrative approach is followed where the propositions of existentialism, derived from the literature, (which is compiled in chapter 3), as well as the different contexts in which the individual exists, (as described in chapter 2), are integrated with the themes derived from the interviews with the participant. The themes that are integrated with those from the participant's are the biological, psycho-social, cultural, gender and political contexts together with propositions of existentialism: self-awareness, being-in-the-world, freedom and responsibility, values, search for meaning, anxiety, death, non-being as well as the awareness of a Higher Being.

5.1.2. *Being born into the world*

The participant, Karabo, was born in her parent's house on 16 February 1962. She is from the Tswana culture and her mother tongue is Tswana. She attended school in her hometown where she completed grade 1 to grade 11, after which she moved to Johannesburg.

5.1.3. *Becoming in the world: family*

The participant's grandparents on her father's side, stayed in town and died during the seventies: "while they were still at a young age in their lives". Her grandfather on her mother's side died in 1970 while her "ouma" passed away in 1995, at the age of 103 years. Her father was born on 16 August 1915 and died on the 3rd of May 1996 (81 years of age). Her mother was born on the 3rd of December 1922 and died on the 14th of September 2003. The participant's parents got married in 1946 and were married for 57 years before her father died. Nine children were born from their relationship, namely six sons and three daughters.

Her oldest brother was born in 1947 and died in 1975. The participant did not know this brother very well. Her second brother, born in 1950, is married and they have two daughters, who were born in 1965 and in 1970. Because he died while he was still young, the participant did not know her third brother who was born in 1951. Her fourth brother was born in 1953, he is married and they do not have children. The fifth brother, born on 30 August 1954, was married and had four children, three sons and one daughter. This brother passed away on the 4th of April 1998 because of a liver disease. The participant's youngest brother was born in 1965, did not get married and had no children. He passed away in July 2002.

The participant's eldest sister was born in 1957. She lived in their parent's house, did not get married and has no children. Her second sister was born on the 1st of September 1959, got married and they have one daughter and two sons. The participant's third sister was born on

the 28th of February 1982 and died on the 13th of October 2005 because of AIDS. She has two children who were respectively born in March 1984 (Kotso) and September 1990 (Nanna).

5.1.4. Being in love: romantically

The participant's first marriage was in September 1982 with John, who was born in 1959. One daughter, Katlego, was born from their relationship on the 1st of June 1985. Their relationship ended after nine years, on 10 March 1990. In May 1990 she met Thabo and they were together for five years until October 1995. For three years after this relationship, the participant was not involved in a romantic relationship. Her second marriage in May 1999 was with Kaya, who was born on 09 September 1963. Kaya died on 7 July 2004 of AIDS.

5.1.5. Being in the world: creatively

The participant was employed as a domestic worker in her hometown between 1983 and 1984. Her daughter was born on the 1st of June 1985 and she decided to stay home with her. She moved to Johannesburg during 1987, where she stayed at her sister's place, south of Johannesburg, where she also worked part-time as a domestic worker. The participant worked at a Dutch Reformed Church in Eikenhof on Fridays. She then started to work full-time, until January 1990, after which she worked part-time again. After this she started to work for a lady, who was a nursing sister at the Health Department until November 1991. The participant was invited to work for her at a clinic in Baragwanath Hospital. She took the opportunity and started to work as a cleaner at Baragwanath Hospital's Medico Legal Clinic, between the 2nd of January 1992 and August 1999.

In August 1999, she started her training as a nurse by attending an auxiliary-nursing course at the Lillian Ngoyi clinic, which she completed successfully in September 2000. The participant worked as an auxiliary nurse at Lillian Ngoyi Clinic from October until December 2000. She

moved to Hillbrow where she also worked as an auxiliary nurse at the C.H.C. between January 2001 and May 2002. The participant then worked at the Hillbrow Medical Legal Clinic between May 2002 and June 2003. On the 1st of June 2003, she went for a course at the Baragwanath Hospital Nursing College until May 2004, after which she went back to the Medico Legal Clinic where she was employed as a staff nurse. The participant obtained her diploma in nursing in June 2005. It is a challenge for her to become a professional nursing sister in the future: "...to be nursing sister as a professional nurse, my future is challenge so I have to face it living positive life, that I can go and be what I want to be. That's what, a professional nurse".

5.1.6. To be healthy...or not to be

Although she is HIV positive, the participant perceives her general health status as good. "My general health is good and my HIV it is positive". Her CD4 count was 350 in September 2005, when she was last tested, which categorises her in a stage between the minor and the major symptomatic phase of HIV. When first tested in December 2004, the participant's CD4 count was 1100, which dropped to 540 in June 2005. She does not use anti-retroviral medicine at this stage but goes for a medical examination every five to six months. During December 2004, the participant decided to test voluntarily for HIV, because her husband died of AIDS and they frequently had sexual intercourse without using any protection. She was diagnosed as being HIV positive.

5.1.7. Being betrayed

The participant's husband never disclosed his HIV status to her. Although his mother was aware that he was diagnosed with HIV/AIDS in 1998, she also did not reveal the news to the participant. She felt betrayed and experienced feelings of anger. "Even on the last day of him he still denied that he was positive, that's why I was so emotionally angry, feeling betrayal and very, very angry". The participant was suspicious of her husband's HIV status and pleaded with

him to have protected intercourse with her as well as to go for testing, but he refused to do so: "...he was sick, he was starting losing weight and he did cough and then I was thinking about his status, but he was denying it". Her husband believed that he was the head of the household and the only one who can make decisions. Within their marital relationship the participant felt that she had no right to refuse sexual intercourse or unprotected sex. "You may not say 'no' for Kaya. When you are a woman in our culture, you may not say no or ask any questions". This belief and behaviour of her husband seems to be contradictory to the participant's experiences of how her parents perceived their gender roles and practices. The participant expressed a sense of powerlessness and hopelessness during therapy, which resulted in feelings of meaninglessness. She feels that traditional gender roles contributed to her being a victim of contamination with HIV/AIDS. The participant still expresses the need to converse with her late husband regarding her being infected with HIV:

...if it was a chance for him to come back and he must just sit down and talk about this, it will be much better for me then. He must just tell me why he didn't want to tell me, to discuss about his status, HIV status.

It nevertheless seems to comfort the participant that she was infected within a loving relationship, as she perceives it. "I loved him so much". However, she regrets that her husband did not trust her and failed to disclose his HIV status to her. She says that she feel that they could have worked through the difficulty together. In the process of awareness, and in creating meaning in her broken reality, the participant tries to find answers to her multiple questions by reasoning that

...he did not want to tell me because maybe he was not ready yet or he was still on denial stage and he didn't even know that if we can talk about it there is a hope. He was losing everything that's why he didn't want to tell me, maybe he didn't want to tell me because he didn't want to make me feel hurt.

And yet her husband did not seem to think that she would be hurt if she became infected. The participant needed to work through a process of forgiveness during therapy. She suppressed feelings of anger towards her husband for infecting her and seemed to rationalise and

intellectualise what she experienced as disrespect for herself. She realised that the expansion of her awareness of her feelings towards being contaminated by her husband is fundamental for her personal healing and growth, and that it might be impossible for her to experience meaningfulness if she does not deal with it.

5.1.8. To be...hope for the future

The participant managed to construct meaning for herself through the creation of hope. She became aware of the freedom to choose what her attitude is going to be towards being HIV positive. The participant also realised that she needs to take responsibility for her health and act responsible if she wants to believe that there is hope for her. "Then I realised that there is a hope after HIV...I'm still strong I can even go strong than this, if I just take care of myself". She made a decision to live with HIV/AIDS. She even says that she hopes for the invention of a cure, which can make a difference in her future and allow her to see her children growing up:

...I've got the hope that one day, I will [be] having a cure for me and then I can stay longer than this, and then I can see future for my children when they going to the Technicon or university, and then I can be there for them and that I know that I've got the hope....

According to the participant she discovered a sense of meaningfulness in hoping for a future in which her daughter can successfully complete secondary school education after which she can further her studies. By doing this, she thinks that her daughter can ensure herself a secure future financially and professionally. This insight gave the participant the courage to foresee a future for her daughter.

5.1.9. *Cracks in the culture*

Although the participant is an African Tswana woman, she grew up with parents whom she experienced as been westernised and whom she feels brought her up with those dominant beliefs:

Okay, my cultural beliefs is, my culture is, I'm a, it's a Tswana, Tswana culture and my beliefs is that my parents did not believe in the Tswana culture they use to believe in Western cultures, because they followed the Western culture....

The participant experienced that the different roles of her parents, as husband and wife did not follow the traditional pattern of male dominance. She says that although her father was the head of the home, both of her parents worked and budgeted together in order to make the relevant decisions. Her father was a priest in one of the "daughter" churches of the NGK (Nederduits Gereformeerde Kerk). It seems to be important to the participant to emphasise that she did not experience her father as a person who physically or verbally abused her mother. According to the participant her parents taught her the value of working hard, which also helps her currently in creating meaning through working and following a profession:

...my parents teach me, is that you know if you are in life you must face the life the way it came. You don't have to hesitate if you are, you don't have enough to feed yourself, you have to go and work and get that, this is how the life it came.

This attitudinal value of "facing life regardless", which she says that she learned from her parents, seems to provide the participant with courage and is one of the motivational factors in her process of constructing a more meaningful life.

According to the participant she seems not to experience an existential crisis because of the inner conflict of Western and African cultures she sometimes experiences. She says she feels that she can successfully marry these two worlds. The participant believes that it is possible to be an African woman, having (some) western thoughts and that this as such does not create a problem for her. "But for me I think it's not, you can be African and having Western thoughts,

because you can just go to school, get graduate and having those, everything you want to do and you have to work for yourself...". During therapy we did however work with her feelings of isolation and aloneness, which she sometimes experiences while being amongst Tswana people, especially when she feels that they are strict in their traditional beliefs and customs, particularly concerning gender and spiritual issues. The participant seems not to share some core beliefs with some people of the Tswana culture and therefore tends to feel excluded from the "ubuntu" experience (African Humanness). Johann Broodryk (2002), director of the Ubuntu School of Philosophy, defines ubuntu as "a comprehensive ancient African world view based on the values of intense humanness, caring, sharing, respect, compassion and associated values, ensuring a happy and qualitative human community life in a spirit of family" (p. 26).

We identified some traditional sentiments, which the participant seems to value and which contributes to her sense of belonging and allows her to experience and create a greater sense of meaningfulness. Examples are: the significance of her hometown and her parents home, her parents graves and belongings she inherited, the family and extended family and taking responsibility for each other, traditional congregational clothes which indicate her role in the church and community, traditional dishes she loves to cook, etc.

Although the participant ponders the value of helping fellow human beings, she seems to have a problem with unconditional "sharing", because it is her perception that some people misuse it. She also finds it difficult to ask significant others for help when she is in need. She often experienced that people she perceives as dependable, ignored her creed for help and disappointed her. The participant says that she believes in a God who will provide for her, in His own time.

...the African it's for to share, but now when I know that, that was really not right, because you can't, you don't have anything but you give somebody who's got so many things ... I think the Western, it's right for us, because you mind your own business ... that's why I said I believe in God, I know that if I need umm and pray, ask God please give me that. Even I'm not going to get it the very same time, but I'm, at the end I'll get it.

She says that she expects life after death, which means eternal life to her; a life without tears, pain, illness and death. As she believes that she is going to be in God's presence eternally, the participant says she experiences a sense of peace and security. Her belief and trust that life does not really end after this life, seems to give her hope and courage to create meaning in the reality that exists for her. She seems to feel that she actually has a future:

...death I think it is the transport for you to get to heaven, heavenly Father, you have to get, you have to die first, then from there you can just see your God and talk to God ... there is life after death, because you have been walking here in, before you die, then after death there is a life there, because you can just be with God.

Death does not seem to be a final destination to her, but a thoroughfare to a better life. This belief of the participant gives her a sense of continuity.

The participant seems to value life and health as precious. She takes care of her own health by eating nutritious food, exercising and living a vigorous lifestyle. She tries to manage her stress levels and read enriching material. The participant says that she feels it is her responsibility to do everything she can to look after her own as well as her daughter's well-being. She reasoned that by making a deliberate choice to be responsible and acting accordingly, she might stay healthy for a longer period of time, which will give her substantial reason to hope:

...health is how do you help your body and mind, umm, health, because it is the life, you have to be health, to be me, to live, to be in life, cause if you are not healthy enough, you can't live, because you'll be sick and that, and that and then you can just die.

Contrary to the traditional beliefs of her culture, the participant views illness as a physiological event rather than a spiritual one: "...I believe that illness is the disease, it's any disease it's not a witch thing or a cast that somebody can cast you and then you can be in illness". The participant seems to experience that many of the people from her culture, believe that somebody who is HIV positive has been cursed and bewitched and that it is only the witch doctor, sangoma or both who can cure an individual:

Ja I know in our culture people will think that if you are HIV you have being cursed or you've have been witched by somebody. So what you have to do, you have to go through the witch doctor, and giving you some medication, some medicine and I, what I know that, that's not true for if you are HIV positive to go to the sangoma or to the witch doctor, because they don't have any cure for that.

She also says that she feels stigmatised in the community because her experience is that many people associate an HIV positive status with immorality:

I think they stigmatise people, because when you are HIV in my community, they tell that you, you are sleeping around, you know that's why they stigmatise people and another thing they believe that you can be witched. Ja and the most things comes to that you are not very good, you've been sleeping around, or you are a prostitute or whatever, or you breaking some people's house and homes and take the people's men and you know those things, that's why they don't like people who are HIV/AIDS.

During therapy, the participant dealt with feelings of rejection by significant others for she experiences that they are accusing her of causing her own illness. This seems to alienate her even more from the community that she says she needs support from. We worked with her feelings of worthlessness and vulnerability due to what she experiences as misunderstandings and unfair condemnations. The values of integrity and high morality seem to be very important to the participant. According to her, she was infected with HIV/AIDS through having sexual intercourse with her husband and was not contaminated because she was the one who slept around, although significant others seem to accuse her of sleeping around. "Like myself I didn't sleep around, from my two husbands, I get it from one person. And I don't know, who, how did he get [the disease] for, and where and when....". She consequently felt cheated and deceived by her husband.

The participant seems to have a basic need to sense the existence of a Higher Being who can guide her in her creation of meaning within the reality that she sometimes experiences as meaningless. In her search for meaning, it becomes apparent that she takes into account, the

possibilities of human “saviours” who might contribute to her search for meaningfulness. During therapy we conversed about the usefulness of traditional beliefs and practices for her construction of meaningfulness. She expressed the need for trustworthy human beings that can inspire, guide and support her. Although the participant seems to be aware of traditional figures, beliefs and rituals, which contributes to the creation of meaning in the lives of fellow Tswana people, she feels that the roles of sangomas, witchdoctors, ancestors, forefathers as well as the customs of circumcision and name giving ceremonies seem not to have significance for her at this stage of her journey.

The participant has found a strong antagonism towards the healers of her culture. She does not believe in the healing powers of sangomas, neither is she of the opinion that a witchdoctor can curse her. She seems not to differentiate between their roles but equates sangomas with witchdoctors. To her they are human beings who cannot fulfil a meaningful purpose in her faith, illness and life. She has adopted a belief in the healing powers of western medical doctors. The participant says that she feels that the same power the sangomas claim they have, could work through her when she prays, although she seems not to perceive these powers as extraordinary:

Ja because really I don't believe in sangoma and witchdoctors because what I know is they don't have the powers ... I can pray God the Creator who can give me the power, like the very same witchdoctor or the very same sangoma. And I know that the sangoma always what they need, they only need money, and they, they lie to people ... but even when you go to the Western doctors and the hospital or the clinic, you can be cured from those doctors, but then those healing people who said they are healed by a sangoma or the witchdoctor, I don't believe on that because what I know the doctors has the powers.

During therapy the participant expressed her need for a supporting system that seems “real” to her and can make a difference for her in the living reality she experiences. According to the participant she needs people and rituals in her life, which are significant to her and will give her

a sense of meaning. She says that to her life is short and she wants to busy herself with beliefs and activities that she believes can add value to her life.

The participant says that she thinks that her deceased forefathers and ancestors are not part of the living world. She seems to feel that she does not need to take them into consideration for her construed reality of the world, nor need she communicate to them or obey their wishes. Her construction of spirituality and a sense of a Higher Being include a monotheistic belief that the Christian God is the only true God and has sole power and sovereignty:

I don't believe on that, because my parents never believed on my forefathers that somebody is there ... for the ancestors I really believe, I don't believe that those people, they are dead, they really dead and they are through ... So if you have to do some work for them and slaughtering sheep or cows for the ancestors, I really don't do that, because what I believe that, is that the Bible I read, cause it, I always read as what I said, don't obey for the ancestors or any god, the only God that you have to obey is the Creator and heavenly God.

The participant says that she needs to have a fairly clear formulation of her belief and cannot afford to dwell in grey areas which might contribute to the many uncertainties she says that she already experiences while living and dealing with being HIV positive. She seems to urge for certainties in life and tends to hold on to these descriptions of her interpretations of truth and how it relates to her experiences of reality in time and space.

5.1.10. Cultural trauma

The participant seems to have ambivalent feelings about the ideology of Apartheid and the way that she feels it affected her and her family's lives. She says that Apartheid challenged her to develop the courage to learn to stand on her own, to work hard for what she wanted in life and to appreciate some Western customs and traditions which she says she finds more acceptable than some African traditions. Her father was a minister of religion in one of the daughter

churches of the NGK, which is still labelled by some as an Apartheid's-church. According to the participant she grew up in an African home where Western beliefs and customs were the order of the day.

...I will just say in the [past] Apartheid, I think it was right for us, because when we grew up, we grew up that we have, we know that we have to work very hard for you to get what you want, and you don't have to go on the street and asking for the money.

The participant rejects belief in the sangoma's healing powers; instead she adopts the western faith in a Christian God. The values that seem to be important to her in her life right now are her Christian faith, attending the Christian church, studying and undergoing further training. She experiences aspects of and artefacts of the western culture generally as meaningful to constructing a life, which is worth living. She believes that a belief in God's omnipotence can help her create hope for her future. She holds onto the belief that His power surpasses all understanding, thus making it possible for her to carry on in this sense of security, which such a faith brings to her life. The participant experiences an existential vacuum, prompted by her HIV status, which has a psychologically draining effect on her. She experiences her belief in Christian divinity as providing an intervention facilitating her ability to cope with her circumstances. She experiences human beings as having disappointed her, she has lost faith in their healing powers:

But now since the Apartheid situation is no longer there, we are really delighted with the Western cultures, because some they believe that our African tradition you must go to the sangoma or to the healer and the Western cultures believes that you have to go to church. When you go to church that's how you are going to get to communicate with God, but now the African one's they clash because they, everybody's thinking, if I'm going to be a prophet I have to go to be a sangoma or to doing that, and some of them they don't believe that you should go to school....

According to the participant there are many unpleasant experiences she recalls from the Apartheid-era. She describes some of these as follows:

You know the bad things in Apartheid, is when you, the white use to do down on the black. You know like in our place, we when I grow up there was this thing, post office, even in the bank, then they said white only, blacks only. Then you can't even go there in the white's door and they will call you by the names you know when you go there

The only one thing I didn't like about the apartheid is when I grow up, when I had to go, a young child, the young ones of the white person, like miesies or a baas, that one make me really, the white people didn't like us, and you know what do you have to do. We had to work very hard for them, and we had to go and work for them, in there, as a domestic worker and they give you little money. And another things, when even you are, you are educated more than her, you, she's going to get a nice job than you, you can't work any where, you can't go to be a consultant in the bank or a manager... And another thing when we grow up, my grandmother use to tell us, that they use to stay in the farm and when they staying in the farm, they were staying metres [kilometres] from the white people's house and the white people they use to go to our, to our grandmother and when they can find them around half past nine not sleeping they will doing something, they are going to hit them, our grandfathers and you know, they will do something very not right to them.

The participant seems to be touched by her cousin's death. She grew up with him and felt very attached to him. She says that police murdered him when they mistook him for another boy and shot him mistakenly. It seems that this multifaceted experience of cruelty, together with other experiences she had of Apartheid contributed to her suffering:

...my mother's sister's son, he had been killed by the white people ... And you know it was really terrible for him, and then he [police] killed these two young boys, at the age of sixteen, seventeen, because they just coming from the shop to buy some matches and a candle, and then the white man killed these two ... They [police] shoot a photo, and they took this photo to the police station and they put it on the wall, and one day my younger brother, he was one of the, the people they use to call them the comrades, and then they call him the comrade and they come and arrest those comrade, and they started showing my younger brother those pictures [of the two boys], that's why my

younger brother get, be traumatised, because he saw those pictures and he realised that this is my youngster, and they shoot him here, in the stomach and everything, everything inside was just out. And then they just traumatised him and said, if you don't tell us the truth we are going to do you, you will be ending you know up like this [the boys on the photo]. Then my father said you know they were so cruel, they were really cruel, because how can they do that?...but after that I realised that ... some white people they are really cruel.

According to the participant her father suffered under the apartheid government and was imprisoned by them. She seems to be closely related to her father and expressed her need for his presence, support and guidance on her journey while suffering from HIV/AIDS. In therapy we worked with her feelings of anger, grief and despair, which contributed, to her experience of a sense of existential vacuum.

It seems that the participant suffered at the hands of the ideology of Apartheid and that she struggled as she experienced existential anxiety most of the time. She initially seems to minimise the damage of apartheid although she gives the above-mentioned poignant description of human rights. Her ambivalent experience of the privileges of Apartheid seems to be less prominent than these memories. It seems as if she has internalised the abuser as a means of coping. This has gone so far as to make her reject her own culture. These practices contributed to existential experiences of being alone and feeling helpless even before she learned that she is HIV positive:

They are really cruel, because I didn't have any option, so I had to grow up and work for them again, and call them miessies, and I didn't have any problem but I'm always having this thing, oh God please help me for those people they mustn't do me the harm, the thing they did for this. Ja that's why I said, Apartheid it was very bad ... they teach me I must stand on my own, I mustn't rely on anybody ... they only give us the strength....

She, however, says that she made a conscious decision not to hate those people but to condemn their actions. "I don't, I don't say I hate those people, but I didn't like the treatment they give us, because it was very, it was not acceptable". The participant also experienced that Apartheid had the implications for her that some white people treated her with disrespect, racism, discrimination, dehumanisation and that she was less privileged. She contradicts her early mild statements about apartheid by saying, "It was really a terrible life for us. Just because you're skin is a certain colour. Ja because of a certain culture". The participant cannot change her skin colour, but she can reject her culture. This may indicate that she seeks the acceptance of her abusers and is looking to be more acceptable in order to escape ill treatment.

5.1.11. Sense of being: a sense of self

The participant felt that becoming HIV positive initially influenced her sense of self as well as experiencing herself as unique. "I know sometimes I become so emotional and thinking of many feelings suicidal and thinking that I'm, I'm lonely and thinking that I, I don't exist sometimes because of this". She feels that she became one of the many HIV positive individuals in this country (South Africa):

It changed my life because I was not the one I use to be, I was just having a, another person now, I'm not a person, the one I use to be or I was just somebody who can just get sick and die anytime ... I am no longer me....

The participant developed the need to become more authentic and to accept her circumstances in order for her to be able to experience meaningfulness. She felt challenged by her work, studies and friends through discovering creative and experiential values, which created hope for her.

In the process of constructing meaning, the participant actually realised that although many aspects of her life did change, she still is the same person with values, which she prefers to

exercise in her daily life. Her work, studies, friends and the church seems to be valuable to the participant and they challenge her to perceive suffering and death in a different way:

Just only the, that HIV status change you, but when I realised that I'm still myself I can do whatever I use to do, I can work, I can go to church, I can meet friends I can talk and I can do everything that someone who's not HIV positive can do it. I can still go to school and do my future, maybe I can just go there and grab it again and do something for myself.

Through the course of therapy the participant developed a sense of courage, which motivated her to work with her experiences of broken reality.

She experienced and exercised attitudinal values by perceiving her new health status in life as challenging: "...it changed me a lot then I just tell myself now I must, I'm in another stage of life, so I have to, I have to face the life the way it challenge you". Although the participant expressed the need for a soul mate, she says that she does not feel ready to become involved in a romantic relationship with the risk to infect somebody else with HIV, as her husband did. Her decision of abstinence contributes to the participant's feelings of isolation. It seems to be difficult for her to create security and safety in relationship with others.

5.1.12. An existential vacuum

The participant experienced acute health problems during July 2005. She currently feels that the severe headaches and acute stress was caused by an awareness of the reality that she already has been ill for one year, and yet is still alive: "...especially after a year, then everything just came back for me". During therapy and in between sessions this realisation confronted her with the reality of her sense of self, values, relationships and psychosocial experiences. She reflected on her life and said that she realised that she does not feel fulfilled at work. She also went through financial difficulties and felt rejected and isolated by family members to whom she

disclosed her HIV status. Her concern and quest of disclosing her HIV status to her daughter contributed to her experience of fear and anxiety:

So and having this thing that I must disclose to my baby, but I couldn't disclose to my baby, I think that the only thing that makes me to, to get sick, especially to having this problem, the headache problem, because I didn't know how I am going to stop and disclose to my baby.

The participant felt that she could not trust anybody to look after her daughter after she passed away because she experiences them as being unable to keep their promises to her while she is still alive. She disclosed her HIV status to her sister who accused her of flirting around. She experienced her sister as only being interested in what she can inherit and not wanting to agree to look after the participant's daughter after her death. She also has a favourite aunt and uncle who seem to disappoint her by becoming less loyal after she disclosed her HIV status to them. She now views them as less reliable and feels that they do not keep their promises to her. She says that she believes that they will not be able to act differently after her death. The participant had severe experiences of feelings of meaninglessness, which manifested in feelings of emptiness and suicidal ideation. "I can just even commit suicide because I was just seeing my life is really empty". She experienced a sense of existential isolation and felt alone:

I was all by myself, I only had the doctor at work and my psychologist, because when I, I talk to them I was feeling relieved, even when I get home I know that I really feel relieved, because I talk to somebody who can understand me and listen to me.

Although the participant is living with HIV/AIDS, she says that she prefers not to disclose this reality to most of her significant others. According to the participant, they are not aware of her diagnosis and therefore probably not deliberately participating in her process of meaning making. She experiences significant others to whom she disclosed her HIV status as not being trustworthy and feels that she cannot share her feelings with them. Her closest friend, with whom she conversed in the past, passed away. The participant says that she does not feel ready and prepared to disclose information on being HIV positive, although she constantly considers conversing with her daughter about the matter. By withholding such a crucial part of

her reality, she often experiences a sense of existential guilt and anxiety. According to the participant she feels comfortable with going for therapy in a confidential environment, although often experiencing it as a painful growing process. During therapy the participant shared her belief that she perceives it as her calling to co-create meaningfulness in her life while being the architect thereof. For her, being able to speak to her doctor and psychologist sustained her even at home where no one related to her.

5.1.13. Being pulled through

Religion and spirituality seem to play an important part in the psychological well being of the participant. Many of the therapeutic sessions were spent on dealing with her spiritual issues and her creation of a sense of spirituality and a Higher Being, which contributed to her meaning making process in time and space. The participant's initial perception of the God she says she believes in as well as His hand in her suffering dramatically changed through the therapeutic process. She seems to accept suffering as an integral part of life, which she also found as being enriching to her sense of self. She says that she discovered that her experiences of suffering contributed to her process of meaning making and added a richer quality to her life. The participant says that she perceives death as a nonnegotiable boundary in life and holds awareness thereof as a basic human condition that gives significance to living. In the process of creating meaning through therapy, the participant came to the conclusion that God "pulled her through". The participant managed to construct some meaning in the midst of her suffering, which she believes she could accomplish through therapy and faith in a Higher Being.

The participant's expression of anger, fear, doubt and questioning, were dominant during the initial process of therapy. We worked with moments and phases of doubt where she experienced the "dark night of the soul" by which she means: a sense of feeling abandoned and forgotten by God, extremely alone in the world, alienated from God and human beings. She said that she experienced the absence of light. It seemed difficult for the participant to recognise and identify her perception of the Christian God she learned to know since childhood

and who was familiar to her. Her pre-conceived ideas about God seemed to have been fixed and she wanted to return to those experiences and perceptions that she previously created of God. She said that she could not understand why the loving God she worshipped, allowed her to become infected with HIV. She struggled with questions in her own mind like: Why do bad things happen to good people? Why does God not bless her righteous ways, but curse her instead? Where was God, whom she believes is almighty, when she became infected? If He is sovereign, how could He allow this to happen? Which part did He play in initiating her suffering?

During the process of therapy, the participant's said that her perception of God broadened as she realised that for her God is a loving God who deeply cares for those who suffer. She says that she believes that He originally created the cosmos perfectly, all in harmony with Him and others but that broken reality emerged after human beings fell into sin. Since then, according to the participant, broken reality emerged, which manifested in illness, destructive relationships, death, etc. According to the participant, every human being has the freedom to exercise her willpower and choices. She reasons that everybody needs to take responsibility for their own actions but eventually has to give account to God concerning the use or misuse of their freedom. According to the view of the participant, people have a choice to respect their own as well as their fellow human being's lives. The participant says that she eventually came to believe that it is not God's will that she is infected with HIV, but that her husband misused his freedom and disrespected her by infecting her. Her interpretations of God's will and her perception of an individual's responsibilities seem to have made it possible for the participant to forgive her deceased husband. She said that she believes that Christ has compassion with her suffering because He came to earth to suffer and die, in order for believers to have eternal life. She said that she experiences Him as the only one who understands her suffering having knowledge of how she feels and who can also foresee the future. During the process of therapy the participant described a sense of the God whom she came to experience as being greater than a definition or dogma.

5.1.14. *To disclose or not to disclose*

The participant seems to experience fear about disclosing her HIV status to her daughter:

That's why I'm so scared for her, because she's too close to me, and we share some things together and she always tell me that mommy I love you so much and you know I don't want to see her hurt ... if you have died now I will be lost, I won't have anybody now.

She perceives her daughter (21 years old) as being a suicidal risk because of the way she says she handled previous crises:

That's why I'm so scared for me to tell her, because even sometimes when we suffer and we have not money, then we don't have food to eat, she use to tell me that, I think no, now we can just go through this or we can commit suicide both of us and then that is the end of us, both of us. That was only my fear for me to tell her, that I don't know how she's going to take it.

Because she feels very attached to her daughter and perceives a sense of self-transcendence as an important value in life, the participant says it is possible for her to create hope. She says she believes that a sense of meaning is not simply innate, but rather that meaning can be created through a commitment to something that is beyond oneself. She reasons that meaning is discovered in relating to others and in transcending one's sense of self.

By living for her daughter she is creating meaning for herself as well as experiencing meaning through loving her. The participant expressed the wish to earn enough income for their present financial and material needs as well as enough pension for the future. The participant is renovating their home in order to make it a safer environment for them to live in. She says that she invests time and money into her daughter's education and supports her acting talent. According to the participant, the existence of her daughter makes it worth for her, to live with HIV/AIDS and she wants to be there for her in life:

You know this thing, ja, the things made me really realise that I have a life, it's my baby, because my baby is everything to me, she's everything to me, because what I look in time, I just said no I still have things to do for her to, for her to expose, for her to be exposed in life. I have to, umm, maintain her for her to go to school, I have to be her, with her when they are going to the first, umm, high school, not the first, first, umm, university or, umm, college or anywhere. So I have to be there for her and financially, I must be there for her, and some of the family especially my brother's children and my sister's child, I think I must be there for them, because those people I think they are very important to me. I, when I look at them I can just see my image, then I said no this is my children.

The participant's love for her daughter is an experiential value she ponders. It seems to cause tremendous inner conflict in her. During therapy, she worked through different possibilities of disclosing her HIV status to her daughter, and is still keeping her options open by not reaching the stage of sharing this reality with her daughter and withholding both of them from dealing with the disease together.

5.1.15. Transcendence: three little ladies

When she is-with-others, the participant has a-sense-of-others, as conscious beings who can reflect upon her and make it possible for her to exist on a level where she can be there-for-them as well. She tends to feel the need to take care of the two children of her deceased brother. The children are in grade 11 and grade 12 and the participant would like to "see that they are going to college. I know I don't afford so much but the little I can give, I think it will mean a lot to them". The participant ponders the experiential value of love and also seems to care a lot for her sister's (who died of AIDS) two girls. It is her perception, that the children are not taken care of and that their caregiver experiences a drinking problem. She has chosen to adopt them in order to provide a sense of love, care, provision and a better life for them. The participant says that she feels that the responsible way to go about the matter is to discuss the possibility with

her daughter, because she will probably be the person who cares for them, if the participant herself is not able to do it anymore. She also says that she feels that the "ladies" (the two girls and her daughter) might need each other as a family in the future. She says, however, that she will not consider the possibility if she is not going to receive a grant for them:

And there are these two children ... and that's my babies, I love them so much especially when the mother died. Then I realised that I, I must take care for them, I must you know take ... to the primary [school] [on] extension level and then he also [can] go [to] the crèche and I'll be the mother for them and you know what ever I had I must share with those children.... If I'm still in life and I'm still going strong, then I must take care of them. And she must realise that she's not the only one in my life, there is some children who I have to take care and she can just learn that even I'm not there anymore, she can continue having the sisters and she can even take care for them, yes ... But I think if they are staying with me, that will be a nice life and then I will be happy this three little ladies around me and then we can be a big family, a family of four, ja.

The participant seems to create meaning through giving her time, resources and care to the children in her family. She experiences hope and meaningfulness when she has these children around her. The participant feels that she is gaining by giving to them, because they make life bearable for her while she is living with HIV/AIDS. She says that she believes that by caring for them together with her own daughter, she is creating a family who will then be able to look after each other, after her death. These children whom she perceives as her family seem to give her a purpose to live for.

5.1.16. Transcendence: universality

The participant is visualising her own hospice where she can support people who live with HIV/AIDS and are experiencing similar difficulties such as meaninglessness, acceptance, disclosing, stigmatisation and the construction of meaning and hope for the future. In order for

her to accomplish this dream of a sense of self-transcendence, the participant says that she wants to further her studies and obtain a diploma with distinction and work hard as a nurse:

...and then I can one day I can have my own hospice or something for me, then I can help those people they are HIV, and those people who not want to accept it, their HIV status. Then I can just get them to realise that even when you are HIV positive, you still can go through and you still can go strong....

She expresses the need to contribute to their creation of meaning in their suffering and experiences of meaningfulness. The participant says that she wants to give hope to other people who are also searching for meaningfulness and might need to construct meaningfulness in order to carry on in life. She wants to share experiences of her journey with them and sow seeds of hopefulness. The participant says that she believes that through a sense of transcending herself and reaching out to others, universality may be experienced, which might contribute to their unique journeys in an enriching way.

5.1.17. Existential meaninglessness: *darkness*

The participant experienced a crisis of meaninglessness, which was explored through a therapeutic process and seems to stem from a dilemma of a meaning-seeking creature that is thrown into a universe that apparently has no meaning. One of the reasons why the participant experienced feelings of meaninglessness is because of her suffering and the estimated terminal prognosis thereof. There were moments in which she considered suicide in order to escape the prolonged suffering that she anticipated could be part of her journey:

I was thinking that if you commit suicide this is minus one problem, because you won't fail life or you won't have any problem on that, because you will be dead and if you have to wait for you to die, it will take time, but if you, you suicide you kill yourself or you commit the suicide it will be much better and quicker.

She says that she wished to escape suffering by dying which immediately, for her, leads to eternal life, freed from pain, suffering and heartache. These were part of her experiences of the “dark night of the soul” in which she felt totally hopeless and was also searching for her construction of the God she says she believed in, since being a child.

The existential vacuum she experienced felt like darkness to her, which lead to hollowness and a sense of emptiness. The loss of her husband, feelings of loneliness, financial difficulties and a lack of hope for the future were some of the reasons that contributed to her experience of meaninglessness:

...I can just call it my life was dark, there was no light there for me, because first thing my financial was very, umm, going through the drain, and even my health, this headache and those things, it was very tough on me. I just say that I, I can't face the life without, with my late husband, because he use to be there for me ... but now when I realised that I am all by myself, that's why I say no, life it doesn't have any meaning ... I have to think about what I'm going to eat, how I'm going to survive with my baby, and buying food or pay the school fees, and pay the bond, that was the things that made me that no life doesn't mean anything to me.

The participant says that she did not experience any hope and temporarily believed that the only way to escape this reality was through suicide: "...what I was just thinking is to commit suicide, 'cause [because] really I can't I was not fit enough to live you see, because life was really terrible for me...." During the time she considered suicide, she says she believed that her daughter would understand that suicide is the only solution for her:

... she will realise that I was not the coward when I committed the suicide, but I have done what I had to do, and that was the only solution I've got in life, 'cause [because] there was really no meaning for me to live.

Apart from her husband's death, she also mourned the death of her best friend, whom she was closely attached to, as well as her cousin, whom she cared for and who also died recently.

These losses seem to let her feel rejected and lonely as she longs to be with those significant others:

My friend passed away, now one of my cousins also passed away, and every, everybody I'm close to, they were just passing away, and then I said no this is not right, let me the life is not for me, I have to, to commit suicide for me to go there, where the people are going, because if without those people, there's no life, there's no meaning in life.

She was angry because of the losses and experienced an existential crisis, which included spirituality quests as she also tended to blame God:

...ja I lost him, I lost her, and those things make me very angry in life. I even, I was even angry to God, then God, I said God why did you do this to me, what did I done in life, for me to get so hurt....

5.1.18. Challenging existence

During therapy, anxiety was confronted as an inevitable part of the human condition. The participant as an appropriate response to being HIV positive has faced existential anxiety. She realised that anxiety need not to be repressed but can be used as a motivation for change and a potential source for growth. This anxiety accompanied the reconstruction of the participant's life and seems to help her to dare to take steps necessary to change the direction of her life. The participant now seems to be able to associate her anxiety with the birth of a new idea.

Eventually, the participant experienced that her sense of spirituality, therapy and support from her medical doctor were some of the instigators which motivated her to change her attitude towards her illness and future, as well as facilitated a process of growth and construction of meaningfulness for her while living with HIV/AIDS.

5.1.19. *Sense of Higher Being*

The participant says she feels that she can bargain with God because she perceives herself as having a personal relationship with Him and experiences Him as present through the Holy Spirit. According to the participant she experiences the Holy Spirit as the comforter; the one who pleads for her with the Father. She feels that she becomes free after laying her burdens before Him. She says she believes that the Holy Spirit enables her conscience to be sensitised to the voice of God and that her conscience has an intuitive nature, which allows God's wishes to become known through mutual communication. According to the participant she also searches for meaning by conversing with God through whom her spiritual orientation becomes meaningful to her as well as authentic and internalised. The content of her faith as well as her sense of spiritual orientation seem to contribute to properties of her religion, which she experiences as meaningful:

...I'm close to God and I can ask God, why do you do this to me, and I know that I won't see God face-to-face, but when I spoke to Him I can just feel the spirit that God is present, the presence of God. That's why I said my religion, I can say I believe on that really, because I can just spoke to God and ask Him and taking all my anger and then I feel free when I talk to Him, no matter I don't see Him face to face, but I believe that He is there, the presence of Him, yes that's what I can believe in.

The participant individually seems to create unique values through the guidance of her conscience. She experiences that these values provide direction for her personal life under all circumstances. It seems that she managed to construct hope for herself and to challenge life. Through therapy she feels able to relinquish and deal with issues like a sense of alienation, defiance, conflict, hope and despair:

...for me to go to the psychologist, and show me, show me that you know you can live with it. And even [the] doctor ... use to tell me, that no we can pull through and I prayed very hard, I pray every night and say God please forgive me, forgive me for doubting You, that You are, and forgive me to be thinking of this suicide. It's how I solved it, I realised that You know if you pray, there is a hope, and something will just remove from

this ideas and that, put something inside your ID, [according to her religious belief, Christ gives a new identity through being re-born] you can have a new ID and then you say no life I can challenge it.

The participant seems to experience her sense of struggle with God as a significant part in her process of meaning making. She nevertheless felt guilty because of her sense of becoming angry with God, bargaining with Him and doubting Him as well as for her suicidal ideation. She engaged in a process of forgiveness that she experienced as setting her free from guilt and enabled her to create a greater sense of meaningfulness.

5.1.20. Being in need for conversation

The participant seems to be dependent on her relationship with others. She wants others to be significant in her world and she would like to feel their presence in her life. As her sisters have knowledge of her HIV status the participant seems to have a need for them to converse about her becoming infected as well as showing a sensitivity for the condition of her well being. Because they do not have these conversations with her, she seems to feel isolated and alone:

Yes, I use to feel isolated very much, because they didn't come to me and phone me nothing ...You know when I phone them, they will just ask me, how do you, how do you do today are you alright, that was that, but they've never come to me and sit down with me and ask me, how do you feel for you to be HIV, then I can tell how do I feel, and then she can tell also that how did she feel about me being HIV.

She has a sense of isolation because she recognises that she cannot depend on anyone else for confirmation. The participant realised during therapy that she is the person who needs to give a sense of meaning to her life and has to decide how to live it.

5.1.21. *Being creative*

The participant's work seems to be very important to her. She says that she feels that she can still work hard and create meaning for herself as well as other people while supervising them:

But if you are still really strong, you can just continue to work yes. And even the workplace, there is the companies who take care for the people who are HIV. Yes, you can create some meaning through work, because you know, when, when I said, if you work, you can even be a supervisor at work, because you create some, umm, umm, space for, for some other ... because if you are HIV positive, that doesn't mean your life stop, you can go continue the life.

She says that she would like to further her studies in nursing and to enter a counselling course. The participant says that she believes in the creation of meaning through work, while serving other people. She says that she perceives her work and studies as callings, which she feels she needs to obey and through which she may be blessed. The participant experiences her work as very fulfilling and feels that she empowers herself by going to work and nursing ill people. This seems to motivate her in life and energise her system.

5.1.22. *Being here and now: a sense of self-awareness and acceptance*

A sense of self-awareness and self-acceptance seem to play an important role for the participant in her construction of a meaningful life. She tends to believe that a sense of self-acceptance may contribute to the process of finding meaning and purpose in life, while living with HIV/AIDS. She seems to realise that the expansion of her sense of self-awareness is fundamental for her growth and the root of her human capabilities.

The life will be worth it when you accept yourself, then you'll be, you'll benefit from that life, because you know that where are you going to and what is your purpose for you to live, especially when you are HIV. You can live with this virus, and you can live positively life. So sometimes you will see that the life doesn't have any meaning,

because you will just be thinking about the things, like committing suicide, especially if you didn't accept yourself.

By increasing her self-awareness through therapy, the participant became more aware of alternatives, motivations and other factors influencing her personal goals. She says that she believes that life has meaning and that there is hope for her. The feeling of self-worth seems to give her the courage to live, to get up every morning and to work. She feels that an increased self-awareness and believing in her sense of self will also make it possible for the family to care for her. The participant says that work, family, people and hope, play a crucial part in her construction of meaning in life:

Life has got meaning, because you will wake up early in the morning going to work and you got your family to look after, you've got many people by your side, and you can even have some people to realise that no life it is having a meaning. And other things which are really important for you to have a meaning for life, a life full of meaning, to believe in yourself to have hope.

During therapy she realised that an increased sense of self-awareness can sometimes become threatening. Anxiety emerges when she feels confronted with the reality of being HIV positive and fears the consequences of the disease for her physical, psychological, spiritual and relational realities.

5.1.23. Meaningfulness: light

According to the participant she believes that therapy and prayer helped her gain a sense of the light shining through the darkness she experienced and made it possible for her to create hope for herself:

You know what give me hope, when I'm starting talking to you Mariette, I have hope and when I pray I have prayed for hope, and when those stages passed they just pass, and then I say no, there is light there.

To the participant, financial security because of her husband's pension also made suffering and concerns of practical nature, lighter and gives her hope that she will manage in the future. "And even at work I'm, I still have the hope that one day they are going to get my money from work, that's why they have to pay for me and then I can pay everything".

5.1.24. Being thankful

The participant says that because she experienced that she was receiving God's help and felt gratitude for what she believed He is doing for her, she developed the need to serve God and also to contribute to courses from which other people and institutions can benefit. It seems that her sense of thankfulness motivated her to serve her fellow human beings through giving what she has to offer:

Then I said oh God you really helped me to go through ... but then I realised that now I have to do something for God, for God to help me going through this. I have to put ... I have to be involved in my church and then I give what ever I have to give ... but when I realise that no, the light is still there, then I said now there is a hope. And all that I've got, I go through, you show me the road and I really, I really appreciate that, because I saw that really.

5.1.25. Isolation and quest for love

In her search for meaningfulness the participant explored ways in which she could reach out to her family in order to develop closer relations with them. She seemed to be desperately in need to identify some family members who would be willing to take care of her daughter after the participant's death. Her family disappointed her by claiming her heritage and money without any consideration for her and her daughters' well being. During the therapeutic process the

participant realised that it might be more realistic not to expect support from her family. Eventually she seems to be 'ok' with this realisation and willing to live with it:

Even they, they've never asked me any more about my status or what is going on in my family, especially those sisters and brothers, but everything is just normal.

During the therapeutic process we worked with the participant's inner conflict between preserving her own uniqueness and centeredness, and at the same time having an interest in relating to other human beings. We worked with her paradoxical experiences of being both existentially alone and related. Ultimately it seems that the participant feels alone. It seems that she also accepted the fact that her family lives far away and that it is not possible for her to spend time with them very often. She is thus in a way detached from them:

I don't believe on that so much, and especially since I'm staying here in Joburg, most of my people, my culture people, they are in Kimberley. So I see them when I go home and chill with them.

The participant seems to mourn the recent death of her best friend. She says that her friend promised to look after her child, if she should pass away. Unfortunately the participant's friend suddenly died, most probably of symptoms of AIDS. The participant described her experiences with her deceased friend as follows:

You know for me a friend, I, I was working with this friend for me, we'll share our secrets, and a friend will accept me the way I am. If I'm sick the friend must be there for me, and if I'm going through the stages the friend must always be there for me. And when I lose somebody then the friend must be there when I cry, who can just talk to me, or they can even phone me, she can phone me at night or whatever. You know I, that's what I call a friend, from a friend what I need, I need trust, the one I can trust. I can even share and then I know that if I die or I pass away, she will be there for my daughter.

Although the participant experiences the need to have a friend who can be there for her and her daughter, if she should die, she does not want to put her heart on a close friendship again. She

says that she is willing to befriend colleagues in the working environment or even have spontaneous contact with others in the vicinity where she lives:

...but I'm not the person who believe in friends ... so at work we can just discuss about work things, and then if I'm at home I do have some people who just, my neighbour we can just share whatever we share, but I won't call them my friends, because really I don't have any friends any more, since I've lost my best and best friend.

5.1.26. *Community of beings*

The community of people with whom the participant feels that she shares the same sense of spirituality seems to be significant to her and plays a crucial part in her meaning making process. She says that at times when she experienced meaninglessness and the "dark night of the soul", she experienced that their support uplifted her, although she has not yet informed them about her HIV status. She somehow experiences a sense of belonging within this specific community and often expresses the need to spend quality time with them:

...I believe in, in the God the Creator, I believe in that and I believe in Christ and the Bible ... He create you in His image ... Ja, ja, because the Bible I read said, the God's father and Jesus is the son, they call him Spirit ... But I believe that the church have played a big role in my life, cause sometimes when I'm depressed, if I go to church I really, I'm okay, I can just take it....

It seems that the participant experiences comfort, healing and enlightenment of her depressive mood when she goes to church. She says that she wants to believe that the community at church is going to be there for her and that they will not reject and stigmatise her when she discloses her HIV status to them:

You know what I expected from them, they mustn't stigmatise me when they know about my status. I hope they are going to be there for me that, like when we, we praise, that Father forgive us ... but they have to forgive me, and I will ask if they can be there for me, you know....

The participant expressed the need for physical contact and hope that the community will still show her care through physical touch and acceptance:

They used to be open with everybody, I can hug them, and you know sometimes we even just kissed, you know in our church, and then I hope they can still do that to me, when I'm sick....

She says that she believes that they will take care of her when she becomes ill, because this is the way they are handling other people who live with HIV/AIDS:

... to take care for those people are very sick they wash them, they bring some clothes ... You know they are doing something for them, that's why I believe that even me, they will be there for me, umm, ja, when they know that I am sick, then they will be there for me.

5.1.27. Being a wounded healer

The participant seems to think that a person who is HIV positive lives with the disease every day and has firsthand knowledge of existential experiences and making meaning thereof. She is of the opinion that people will probably take her seriously when she shares her story with them for it has credibility because she is personally involved in living with and making meaning of HIV/AIDS. She experiences herself as being wounded but at the same time engaged in a process of healing. According to the participant she is an incarnated example of being an African woman who is HIV positive and who wants to construct meaning together with significant others, while living with the disease.

The participant says that she believes that her faith gives her a sense of hope and makes it possible for her to survive. She feels that she might be able to heal others through her psychological strength and faith:

Yes, my faith, umm, I benefit from that, because I, I have the faith that one day I will reach there, and one day some people they are going see me as a healer, because I do have the faith that I will, I will make it. I won't just go back to like think like I use to think, but because I have this faith that you know God is there with me and I'm going to pull through ... but now because of my faith, that's why I'm still existing now....

5.1.28. *On death and dying*

The participant read through Elizabeth Kübler-Ross's book: *On death and dying* (1997) and says that she feels that she moved through the stages of denial, bargaining, depression, anger and is now in the stage of acceptance. She realises that if she decides to disclose her HIV status to her daughter, the possibility exists that her daughter might also move through stages while dealing with her mother's illness. During therapy, the participant and therapist worked through anticipated probabilities around the daughter's possible responses and reactions after hearing that her mother has HIV/AIDS. The participant says that she wants to disclose her HIV status to her child when she feels prepared for it and decided to realise that during a therapy session. We spend many therapy sessions in conversation about disclosing her HIV status to her daughter:

Umm, you know now I can listen, I, I pass already the stages, I accept it, really because I, I, before I use to not, I was so very angry and bargaining, and I use to ask God why, why me ... that if somebody reject me now, umm, what about my baby, they going to reject her, so she's going to suffer my consequences. So for me to go through I must just look at my baby and go through for her, be there for her.

Death initially seemed to threaten the participant and resulted in feelings of hopelessness and meaninglessness. She created a sense of meaning through therapy while contemplating the boundaries of life, namely birth and death. The participant says that she does not perceive death as negative but holds awareness thereof as a basic human condition that gives significance to living. She seems to grasp the reality of the future and the inevitability of death

simultaneously. She realises that life becomes insipid and meaningless if she tries to defend herself against the reality of her eventual death. Because she realises that she is mortal, she knows that every moment is crucial for her. The participant's awareness of death seems to be to her a source of zest for life and creativity. Death and life seems to be interdependent for the participant. She tends to realise that although physical death destroys her, the idea of death saves her.

The participant says that she is not afraid of death and that God will open the door for her to eternal life:

...if the death is there, and said you must go inside the door and after the door you be dead, I'll go for it, because I know that side there is a life, behind those door, there is a life there. I won't say I'm afraid to death, to die, no I'm not, I'm not afraid, because that's what I realised that after death there is a life, because if I've God now, in this death stage, I will pull through it. I think I will make it, that's what I believe in and now I'm going through and I will go only through when I go through God, that's what I believe....

The participant says she would prefer her daughter to care of her when she starts to manifest symptoms of AIDS and would like the therapist, her doctor and the people close to her, to support her:

You know I would like if Katlego can take care of me, then people who are close to me, like the doctors and yourself and some of my sisters at the church they run it, that they can look after me....

During therapy the participant shared many meaningful experiences of her childhood years in her parents' house. She seems to feel secure and safe when visiting her hometown and her parents' home where her one sister currently lives. For her to spend the last part of her journey in this home may feel like a homecoming to a certain extent. She says that she does not wish to go to a hospice during any stage of her illness and would like to stay at her own home or that of her mother's:

I don't want to go to the hospice ... not for them to take me somewhere, because they are going to kill me, if they remove me from my house, from my home and take me to the hospice ... but for me to be happy and to die in dignity, if I'm at home I must be at home, I don't mind if they can take me to my mother's place in Warrenton....

5.1.29. *Being cared for*

The participant says that she would like to be cared for at home. She prefers to be with people whom she has a personal relationship with. She would like to be in a familiar environment within which she feels safe and secure and wants to continue with life and activities, which her health allows:

I think if I'm at home and I must be sick at my place, then I can get the treatment, and then if I am very, very sick I can't move by myself, they must bath me, they have to make me beautiful like, putting, I don't put the make up, but just to plait [comb] my hair, or doing something and put, put on my clothes, my nice clothes, you know if it is a night dress, it must be pyjama, nice pyjama and slippers and then they can take me to the lounge and sitting there look for the TV. They can take me if I'm still strong enough to go to church, they can take me there, if I'm not, people from church they can come and stay with me, sitting with me and sharing something from the Bible.

She wishes her last stage of her journey of suffering, not to be extended for too long because of the anticipated trauma she says that she believes that the children might experience:

And then if Katlego she's there I will be very impressed, because she will see me going through all this stages until my death, and then even those two Kotso and Nonna if they can see me, then I, I hope I won't be somebody who is really very, very sick, that my child will be having those trauma. I hope I'll be sick and then it must go.

5.1.30. *Disclosure before non-being*

The participant says that she accepts the responsibility for disclosing her HIV status to her daughter and anticipates that she might feel angry, neglected and shocked:

The possibilities they are going to be hard for her to accept. I think it, ja, it will be a difficult thing so, to accept it and because she's, what I think is she's just going to feel that, I, I was not fair enough to her, because maybe I should have told her a long time ago, the time when I tell them that I'm HIV positive, maybe I should tell her, maybe she's going to ask or be angry for me, that why you didn't tell me when you get the results for the first time....

She expresses an urge to experience her daughter's acceptance of her after she disclosed her HIV status to her:

What I want to say, I wish if Katlego she tell me, she accept me the way I am. The day I disclose to her, telling her that I'm HIV positive, if she really, really accept me and she knows that I love her very much, it was not that I was asking for me to having this, because of love, because I get this through love.

The participant says that she feels it is important to disclose her status to her daughter before she shows symptoms because she would prefer to be there for her when going through different stages of handling her mother's illness and anticipated death:

That's why I said I must tell her, before I got sick ...Yes I didn't plan, plan to disclose for her, even I don't know when and how, but I think the sooner the better, I must disclose to her. Then I must know the, how she's going to feel, before Kotso and Nonna come starting to stay with us, I think I must tell her....

5.1.31. *Being hopeful*

Although the participant has an awareness of her non-being and death, she still has the hope that she might see her children grow up:

I wish God give me the strength, God give me strength for me to see my children grow up and God give me a life for me to go another years, I will be the happiest one. And physically I must be strong....

5.1.32. *The unbearable lightness of being*

The participant says that when she feels prepared she wishes to share her journey of searching for meaning and hope with the community, maybe in her hometown as well as in her congregation. "I can go and tell them that if you are HIV positive that is not the end of the world; you can just go a long way, yes".

The message the participant says that she wishes to share with people living with HIV/AIDS is:

So if you are HIV positive, really what I've realised now, that you can live the life without the fear and you must be strong inside you, and what you have to have, you must have hope that one day life is going to be okay for you, umm, HIV disease is not a curse it's never been a curse. What you have to do is that you must know that God loves you, and people around you who loves you, they can be there for you. Then if you only disclose to them and what another thing, you must never be afraid to stand up and to tell that you are HIV and accept yourself, because if you don't accept yourself now, nobody is going to accept yourself. Start loving yourself, and have positive answers, and look the future the way it came to you, you don't have to be afraid anymore. Umm, HIV status, HIV positive just like any disease like, umm, people who've gotten this hypertension, diabetic, even cancer, because you can still going to the clinic and get some treatment. So if you are HIV positive, at least know that there is hope, the cure we will get it at the end, but please don't go and sleeping around. You have to really

take care for your, your health. Even you are stressed, but just ignore some of the things, then you can go through it.

5.2. The future: Being open ended...

The participant says she prefers the researcher to keep the tapes and content thereof confidential until she feels prepared to disclose her status to more people and ready to share her journey with those who have similar experiences:

Okay no the thing, I think you can keep the tape, umm, for confidential and then one day if everything go through ... and I think maybe some, someday you will take it to some people, to listen this and then those people when they listen maybe they going to be good, and realise that there is somebody that knows, she's HIV positive and she's still strong, by that time maybe I'll be still going strong ... maybe we can just meet and share some of the stories....

It seems that the participant experienced the sharing of her journey, through interviews, as meaningful and that it gave her a sense of feeling relieved, afterwards. She seems to feel 'ok'. "I, I'm really relieved, you know, I'm really relieved ... Ja, I'm really okay, I really appreciate this...."

CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS

6.1. Reflective conclusions

This mini-dissertation is an in-depth case study of an African woman's existential experiences and her creation of meaning while living with HIV/AIDS, imbedded in the multi-contexts within which she exists. A woman's search for meaningfulness, while being HIV positive has been explored and discussed and the findings related to key propositions of existentialism. The approach to the study is a postmodernistic attitude with constructionist trends. A qualitative research methodology is followed which explored and facilitated a process of interpretation resulting in thick description drawing on existential concepts derived from semi-structured interviews and a counselling therapeutic process, prior to the research.

Chapter 1 introduces the phenomenon being investigated and provides the reader with a concise overview of the participant's history as well the emerging therapeutic relationship between them. The research aims and objectives of the study are provided and include "to explore and describe a woman's search for meaningfulness while being HIV positive, and to relate these findings with propositions of existentialism embedded in the rich context within which she lives" (p. 8). The approach to the study is described as a postmodernistic attitude with constructionist trends.

Chapter 2 consist of a literature review which explores theoretical resources on the reciprocal process and relatedness of the different contexts within which the participant exists. The impact of the biological, psychosocial, gender, cultural and political contexts on each other, is described.

Meaning making, primarily from an existential viewpoint has been investigated in chapter 3. Proposition of existentialism which were elaborated on are: being-in-the-world, self-awareness, freedom and responsibility, creation of meaning, meaningful relationships, values, anxiety, awareness of death and non-being, as well as a senses of a Higher Being. Western and African

worldviews and indigenous psychology as well as the intersection of culture with personal meaning systems, are explored through a review of literature. The chapter concludes with a discussion on existentialism and HIV/AIDS.

The methodology and ethical considerations of the study are discussed in chapter 4. The researcher pre-selected an information-rich case in order to obtain an in-depth perspective on the case and provide a thick description thereof. Data was obtained from transcribed semi-structured interviews and process notes of the therapeutic process. Interpretive data analyses followed which include steps of familiarisation and immersion, inducing themes, coding, elaboration as well as interpretation. An existential philosophical point of view was used to identify themes.

Chapter 5 provides an integrative thick description of the themes derived from the participant's search for meaningfulness, integrated with an existential perspective on the phenomenon, imbedded in their multi-contexts. Extracts of the interviews are used to elucidate the participant's existential experiences of being HIV positive and making meaning thereof.

The researcher experienced that a trustworthy therapeutic relationship was initially established between the participant and herself within the therapeutic context. This relationship evolved into a process of collaborative participatory interaction, which was enriched by conversing and reflecting on key concepts of existentialism, the narratives of philosophers/psychologists as well as the unique meaning that the participant created thereof. In her construction of living with HIV/AIDS meaningfully, the participant's experiences are imbedded in the richness of the context within which she lives.

Searching for meaningfulness is an ongoing process and may consist of meaningful moments as well as, sometimes a sense of meaninglessness, as in the case of the participant. Nevertheless, the participant used her freedom to choose her attitude towards being HIV positive and re-defined her life, in the foresight of death, as somebody who is not dying from HIV/AIDS, but as a human being who is living with HIV/AIDS. Although every human being has

a unique creation and construction of her experiences of living or dying with HIV/AIDS, the thick description of the researcher's interpretation of the participant's journey may conceptualise and contribute to others' search for meaningfulness in similar, though, uniquely constructed quests.

For the researcher, this research process has been a meaningful experience! "The personal story of someone living with HIV presents a powerful message" (Van Dyk, 2005, p. 99).

6.2. Recommendations

On 30 November 2001, Archbishop Desmond Tutu stated:

It is important that we recognise that we are facing a major crisis and that we want to invest as many resources as we did when we fought against Apartheid. This is not a state of emergency but is a national emergency (as cited in Gumede, 2005, p. 148).

South Africa needs to face the challenge to create a comprehensive, holistic AIDS-treatment programme in order to upgrade the existing healthcare infrastructure, the recruitment and training of health workers, as well as the development of a well-coordinated national programme for HIV tests and counselling (Gumede, 2005). The government and the president, by name, play a crucial role in removing the obstacles, which stand in the way of the facilitation of behaviour modification, and greatly diminish the dedicated attempts of sex educators to protect another generation of across-the-board infection.

Gender related beliefs and relations are far from being democratised, although South Africa has one of the most progressive Constitutions and Bill of Rights in the world. This study showed that there are substantial links between gender-based power inequalities and the risk of South African women contracting AIDS. By reducing gender inequalities, making men more respectful of women, and women more assertive, AIDS can be fought against and a society can be build where women can exercise their right to human dignity (Urdang, 2001). Concerning the AIDS epidemic, deaths can be prevented by empowering women and guaranteeing them economic

and social rights (Gupta, 2001). Empowering women and strengthening them as decision makers of their own lives increase power in households and entire communities. In addressing the contexts within which women live, the position of women in families, communities as well as the country, will be strengthened. As meanings and interpretations influence our communications, the description of a decent African woman, needs to be re-defined (Esu-Williams, 2000).

From a research point of view, literature shows that studies have been done regarding African culture, traditions, worldviews and paradigms from the viewpoint of writers representing Western dynamics. The origin and roots of Existentialism lies within the European context. Research needs to be done by African women concerning their perceptions, conceptualisations and experiences of living with and making meaning of HIV/AIDS in the South African context. This enculturation of theory and practice will give legitimacy and “cultural validation” (Enriques, 1989, as cited in Eskell-Blokland, 2005, p. 78) to research regarding the praxis of a woman's search for meaning while living with HIV/AIDS within the South African context.

Although it is of the utmost importance to sensitise people to the pandemic of HIV/AIDS in this country, people also need to be aware that they can live a meaningful life while living with HIV/AIDS. Much research is done with a focus on the physical and psychosocial aspects of living with terminal diseases. However, living with HIV/AIDS in the South African context is different from a life with other terminal diseases, “as it is bound up with very potent, social and private constructions of disease linked with stigma, shame and prejudice” (Goldstein, 2004, p. 270). In-depth exploration of lived experiences with HIV/AIDS imbedded in the richness of multi-contextual dynamics within South Africa as part of a multi-verse, needs to be done from individual as well from collective perspectives.

This study showed that spirituality and the sense of a Higher Being might play a substantial role in an individual's search for meaningfulness while living with HIV/AIDS. Spirituality as well as the sense of a Higher Being may be relevant for the internalisation of beliefs and values, as well as the integration thereof in the reciprocal process between interrelated systems in the different

contexts within which an individual exists. The relationship between psychological and spiritual aspects when living with and making meaning of HIV/AIDS need to be further explored and conceptualised specifically in South African where a unique merging and/or conflict between Western and African beliefs might occur in individual and collective dynamics.

The researcher agrees with Bakker (1999). Psychology can be a healing art. A psychologist can be a person with a calling, who recognises the sacred and the numinous as part of life! A healing relationship can emerge between a psychologist and a woman who is searching for meaningfulness while living with HIV/AIDS. Meaning making can be created and facilitated throughout the research process.

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APPENDIX A: QUESTIONNAIRE FRAMEWORK

1. Biographical information

- Date of birth, place of birth.
- Culture group.
- Home language.
- Birth names.
- Where have you lived since you were born up till now?
- First marriage: name of husband, age, children, years married, divorce date.
- Second marriage: name of husband, age, children, deceased (year).
- Parents: names, age, deceased, years married.
- Brothers: names, ages, deceased, children (names, ages).
- Sisters: names, ages, deceased, children (names, ages).
- Names, ages of other important members of the family, deceased.

2. Professional background

- Have you attended school?
- During which years did you attend which schools and grades?
- Where and when have you worked since you have started to work for the first time, up till now?
- Have you studied after school or undertook courses?
- Which qualifications do you have?
- What would you like to do in the future?
- How do you feel about the future?

3. Health status

- General health.
- HIV-status.
- Phase of HIV, CD4 count.
- Medication you use.
- When were you diagnosed with HIV? Where?

- What made you realise that you need to go for an HIV-test, what kind of procedures did you follow? Pre-test, test, post-test? Have you received any counselling?
- How did you become infected? How do you feel about being infected with HIV?
- Have you disclosed your HIV-status to anyone? To Whom? When? Why? How did they react to the disclosure?
- How do you feel about being HIV positive? What kind of emotions have you experienced since you realised that you were HIV-positive up till today? How do you feel at the moment about being HIV-positive? How do you feel about the future?

4. Cultural beliefs

- To which culture do you belong?
- Tell me more about your culture and the traditions within which you have been brought up in. What does your culture believe in terms of: life, death, life-after-death, illness, health, name ceremony, forefathers, ancestors, suicide, witch doctors, sangomas, cleansing rituals, circumcision, HIV/AIDS, work, religion, meaninglessness, meaning, hope, family, children, friends? Do you have the same beliefs as the people of your culture? Do you take part in their traditions? Are there any other traditions that are important to you?
- How do you feel about the country in which you live? In which way did the "Apartheid-era" influence you and the people who are close to you? Do you live and work differently from the way that the people in your culture do? Does it create problems for you? Is it difficult for somebody who is from an African culture to live and work in a country where Western customs are dominant? Does the Western and the African cultures clash?

5. Spiritual beliefs

- Are you a religious person? Why would you say so?
- What do you believe?
- To which church do you belong? In which manner are you involved in church activities? How often do you go to church services?
- Which role does the priest play in your life? How do you experience the other believers in your church?
- What does your faith, God and the church mean to you, while living with HIV?
- What kind of difficulties did you have with believing, trusting?

6. Support system

- Who are the most important people in your life? Why do you say so?
- Who would you like to take care of you if you may need it in the future?
- In which way do you want them to take care of you?

7. Meaningfulness

- What does meaninglessness and hopelessness mean to you?
- How do you feel when you experience a sense of meaninglessness?
- Do you feel that life is worth living for?
- If so, what makes life worth living for?
- How would you create a meaningful life?
- Who do you want to be part of your meaningful life?
- Do you think that it is possible for you to make meaning of living with HIV/AIDS?
- What role does therapy and a therapist play in constructing a meaningful life?

APPENDIX B: CLUSTERS OF THEMES AND SUB-THEMES: INTERRELATED WITH RELEVANT ISSUES

1. Being in the world

- **Physical health status (Umwelt)**

Treatment.

Healthy lifestyle.

Being HIV positive.

Disclosing.

Stigmatisation.

Mortality.

Death and dying.

- **Culture (Eigenwelt)**

African and Western affinities.

Customs.

Beliefs.

- **Political context (Mitwelt)**

Apartheid Regime.

History of contamination.

2. Extended meaningful relationships

- **Family and extended family relations**

Family background.

Parents.

Siblings.

Marital relationships.

Being a mother.

Responsibility towards extended family.

- **Support system**

Loss of soul mate.

Isolation.

3. Values

- **Creative Values**

Profession.

Further studies.

Financial difficulties.

- **Attitudinal Values**

Pain.

Guilt.

Death.

- **Experiential values**

Love.

Self-transcendence.

4. Sense of a Higher Being

Internalised beliefs.

Conversations with God.

“The dark night of the soul”.

Content of religion.

Values.

Church.

5. Co-creation of meaning through therapy

Therapeutic relationship.

Constructing meaning through therapy.

- **Psycho-social experiences**

Anxiety.

Depression.

Anger.

Denial.

Despair.

Fear.

Disappointment.

Aloneness.

Meaninglessness/Meaningfulness.

Hopefulness/Hopelessness.

Thankfulness.

6. Awareness of death and non-being

Death.

Mourning/Grief./bereavement.

Suicidal ideation.

Meaning in suffering.

7. Anxiety as condition for living

Existential anxiety.

Normal anxiety.

Neurotic anxiety.

8. Capacity for self-awareness

Boundaries: birth and death.

Freedom to choose.

Responsibility to life.

APPENDIX C: INFORMED CONSENT FORM

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MAMELODI CAMPUS

DEPARTMENT OF PSYCHOLOGY

January 2006

Participant Consent Form

Research title: An existential perspective on a woman's search for meaning, while living with HIV.

Project leader: Surname: Bezuidenhout

Name: Mariette (M.D.)

Address: The Oak nr 14, 77 Rose Street,
Riviera, Pretoria, 0084

Telephone no: (011) 4893822

I appreciate your willingness to be interviewed for this research project. The purpose of this research is to explore a woman's search for meaningfulness, while living with HIV.

Your participation will entail individual semi-structured interviews with me. The interviews will be recorded to allow an accurate analysis of the conversation at a later date. No person other than me will have access to the interviews on the tapes after being transcribed. Only quotes from the transcribed document will be used to explain to the reader your experiences, verbalised in your own words, according to our agreement.

I shall contact you to arrange for a time for the interviews to take place.

Your involvement in this study is voluntary, you are not obligated to divulge information you would prefer to remain private, and you may withdraw from the study at any time. You or your family will not be identified by name in any documentation, including the interview transcripts. According to your preference, you will be referred to in the documentation under the code name, Karabo.

It is expected that research about the phenomenon with its shared, as well as individual experiences can make a fundamental contribution to individuals who are faced with HIV/AIDS on a daily basis. The outcome of the research will be communicated to communities, according to your preference, where individuals might benefit from your search for meaningfulness. This process of the communication of the research findings will continue, when you feel prepared for it. According to our agreement, you will converse with me when you feel ready for this process, after which we will converse about the possibilities and the practicalities thereof. This will be an informal, collaborative arrangement and may even happen at a later stage.

There are no preconceived personal risks attached to your participation in this study. However, if you wish, for any reason, to follow up on issues that emerge for you during the interviews, we agreed upon follow up consultations, if you so wish.

The research findings will be made available to you, should you request them.

Declaration of the participant

I am willing to be interviewed for the research project. My involvement is voluntary. I understand that my participation is, and that information divulged by me will remain confidential and that the quotations from the transcriptions (which are included in the thick description of my experiences, as part of the thesis), will not identify my family or me. I understand that I may withdraw from the study at any point I wish to, with no further obligation on my part.

Participant

Date

M.D. Bezuidenhout (researcher)

Date

