DECONSTRUCTING THE MYTH OF HIV/AIDS: ONE MAN'S STORY

by

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I declare that ‘Deconstructing the myth of HIV/Aids: One man’s story’ is my own work and all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

Ilse Robbertse

Date

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ABSTRACT

HIV/Aids is a worldwide pandemic and as South Africans we are at the epicentre of this global health crisis. The harrowing statistics are useful as a means to quantify a horrific situation; however, what these facts do not do is provide connection amidst the uncertainty surrounding the disease. This research aims to bridge the disconnection and break the silence that weaves a net around the illness and those infected by it. This is done by deconstructing one man’s story of his journey with HIV; by looking at his personal epistemology; and by contextualising his story within his family and within the society in which he lives, South Africa. Finally, it is my reflections and interpretations that form the bridge between a construct of HIV/Aids and a life lived with the disease.

Key words:

HIV/Aids, case study, postmodernism, narrative theory, South African discourse, stigmatisation, discrimination, disclosure, silence

CONTENTS

Africa needs healing…AIDS beckons us to the fullness and power of our own humanity. It is not an invitation we should avoid or refuse.

Edwin Cameron – HIV positive South African judge and author (2005, p. 215)

CHAPTER 1

INTRODUCTION

I read about Aids in the newspaper. I knew the extent of its spread...and yet despite being gay, thirty years old, and a resident of the country with the highest infection rate in the world, I was completely ignorant about the realities of the disease...Like so many of us, I was a victim of the secrecy and ignorance surrounding what has become the world's most pressing concern.

Adam Levin – HIV positive South African (2005, p. ix)

This research is about the story of one man who is living with HIV. My journey began with a desire to gain a better understanding of the HIV/Aids pandemic that is sweeping through every corner of South Africa. It was this search that led me to David; and it was David who opened the door for me to construct an understanding of what it means to live a life being HIV positive, by allowing me to accompany him for a short while on his journey with HIV.

As I progressed with this research my focus shifted and it became much more about David's story and much less about HIV/Aids. Mair (as quoted in Snyman, 1998, p. 3) writes:

> Stories are habitations. We live in and through stories. They conjure worlds. We do not know the world other than as a story. Stories inform life. They hold us together and keep us apart. We inhabit the great stories of our culture. We live through stories. We are lived by the stories of our race and place...We are, each of us, locations where the stories of our place and time become partially tellable.

Further to that, our stories reflect the internalised myths that are created by and upheld in the communities in which those stories live. I believe that David's story is particularly relevant in a country that is weighed down by this disease. I also believe that his story is one that sheds light on the profound impact that the discourses of the society in which we live can have on one individual. Most importantly for me personally, listening to his story has allowed a wondrous learning in which my own story now has change. I only hope that I will in turn have touched David's story in some small way.

In the following paragraphs some context markers to David's story and my own journey will be discussed briefly. Thereafter the frame of reference of this study will be outlined, and the aims and the rationale for the study will be addressed. Finally, a brief overview of the chapters which follow will be given.

South Africa: 2008

Recent statistics show that sub-Saharan Africa is the region in the world that is most affected by HIV and Aids. South Africa is regarded as the country which is experiencing the most severe HIV epidemic in the world. The United Nations 2008 global report on the HIV and Aids epidemic stated that in 2007 there were an estimated 5.7 million adults living with HIV/Aids in South Africa, that is a total of about 18.1% of the population who are estimated to be HIV positive (Aids Foundation South Africa, n.d., HIV/Aids in South Africa).

My Journey: 2008

I am an HIV negative South African woman, and until recently, I did not personally know a single person who is HIV positive. To me HIV/Aids has always been a dreadful and serious problem that this country, and the world, was trying to deal with. But it was something that existed “out there”. I now believe that as a South African this is a topic that I, and probably all of us, need to personally grapple with and deconstruct, both at the level of the individuals living with the disease and at a relational level, as these individuals do not live in isolation but live within the context of their families, social groups and society at large.

Based on my knowledge of HIV/Aids and the generally known abovementioned statistics, I cognitively understand that I am a member of the society in the world experiencing the greatest HIV pandemic. I understand that we are at the epicentre of a global health crisis. Emotionally, however, I realised that I do not understand it at all. In asking myself why this was the case it dawned on me that something was profoundly missing. For me to make a personal connection with the illness a “voice” was needed through which I could hear and get to know HIV/Aids. The facts about HIV/Aids, as real and terrifying as they are, exist only as a means to quantify a horrific situation. What these facts do not do is bridge the disconnection, the uncertainty and the stigmatisation that has emerged in our society regarding not only this epidemic, but more specifically, HIV positive individuals in our society. Facts also do not break the silence that weaves a net around the illness and those infected by it.

I believe that a real understanding can only be gained by entering into the world of someone who is living with HIV/Aids. As I am invited into one such world, through one man’s story, I have taken a step from a place of ignorance and distance towards one which allowed for personal experience and learning, and thus a new understanding.

It is only though David’s strength and courage that this research was made possible. His trust in me and his willingness to share his difficult journey with me is what this research rests on. It is therefore my deep-seated hope that this experience is a positive one on David’s journey, or at the very least that it has provided him with a new thread to add to the tapestry of his life.

The Frame of Reference of this Study

This research is anchored in postmodern ontology, a constructivist epistemology and a social constructionist paradigm:

- This study focuses on how one HIV positive individual describes and constructs his world, and how he creates meaning and a personal reality. The approach is that context, including family and societal discourse regarding HIV/Aids, informs these realities and meaning systems.
- The story told is understood as being co-created within the context of the interview. This co-creation is a social construction of both my own and the participant’s narratives and punctuations, and as such informed both the interview and research findings.
- The process of hermeneutics results in the deconstruction of the participant’s story and a reconstruction from my subjective perspective, whereby themes are identified and discussed from my frame of reference.
- I assumed a position of “not knowing”, thereby allowing the participant to be the expert about his story and his life.

Research Aims

The main objectives of this case study are anchored in the previously mentioned frame of reference and include the following:

- To begin to explore some of the richness of the many individual stories of persons living with HIV/Aids, by hearing one man's story and by uncovering his personal experience of living with this disease. This includes an exploration of his journey with HIV for the past 23 years, his struggles and challenges, his coping strategies and victories, and his vision for the future. This is done using a case study approach.
- To uncover some of the underlying ideas and beliefs that people in South Africa hold regarding HIV/Aids, as experienced by the participant, and to deconstruct the impact of these societal beliefs on him. It is an exploration through one man's lens, by unpacking the effects of socially constructed beliefs about HIV/Aids on his meaning systems, perceptions and realities.
- To gain a holistic understanding of what it means to the participant to live being HIV positive.
- To allow me to explore my own perceptions and realities around HIV/Aids and enable me to recognise, challenge and re-story some of these meaning systems, by exploring and deconstructing the participant's meaning systems and life story.

Overview of How the Content Matter is Approached

A comprehensive overview of the current research and literature on this topic is presented and critically discussed. This includes looking specifically at literature regarding HIV/Aids and social discourse about it in South Africa, as this forms the context and background in which this research, the participant's story and my journey are anchored.

David's story is co-evolved from semi-structured interviews between me as the researcher and the participant. I adopted a non-directive and non-evaluative stance, allowing the participant to tell his story from his frame of reference. Some structured questions and specific themes were included based on the literature findings and on relevant themes that emerged through the interview process. All interviews were taped and transcribed. Detailed biographical information about the participant is included, such as his personal history and genogram. A hermeneutic discourse follows, in which the content of the interviews is deconstructed and explored in terms of the dominant themes that emerged. Ethical guidelines are followed, where the participant's anonymity is protected. To ensure this, the narrative excludes identifying information and names have been changed. Lastly, the participant gave written permission for the interviews to be recorded and transcribed for the purpose of this research.

The following is a short overview of the chapters that follow:
Chapter 2: An exploration of the ever-changing meaning and understanding of HIV/Aids within the South African context. This is done by looking at the cultural belief systems and the broader social context in which these meanings emerge and are formulated, and by highlighting some personal accounts of individuals who have lived with the disease.

Chapter 3: A discourse on method. The epistemological lens which informs this research is considered, and the research design and methods are outlined.

Chapter 4: A collage of three narratives. The first comprises my personal experience in meeting David, the second encompasses David's story and the third is made up of the numerous themes which emerged through our dialogues.

Chapter 5: A weaving together of my reflections of the themes that emerged through the research process, including those within the participant's and his family's story, and my own journey.

In the following chapter, a brief literature review of the evolving meaning of HIV/Aids in South Africa is provided by looking at societal discourse and HIV/Aids as an epidemic of stigma. Furthermore, a concise exploration of living with HIV/Aids is presented, with a specific focus on disclosure and by providing an overview of the stories of two South Africans who are living with HIV and one who has died of Aids.

CHAPTER 2

LITERATURE REVIEW: THE EVOLVING MEANING OF HIV/AIDS

By all accounts, we are dealing with the greatest health crisis in human history. By all measures, we have failed in our quest to contain and treat this scourge.

Nelson Mandela (Aids Foundation South Africa, n.d., Quotable quotes)

The aim of this literature review is, firstly, to give an outline of the evolving understanding of HIV/Aids in South Africa, secondly, to consider the meaning of health and illness, and how it informs current discourse on HIV/Aids, and thirdly, to place this discourse in a broader cultural context by looking at stigmatisation, discrimination and cultural belief systems within the South African context. Lastly, because this research is a case study, the review is concluded with reference to the personal narratives of three South African individuals, two who are living with HIV and one who has died of Aids. This review is intended to serve as a platform for the design of the case study research.

Aids, or acquired immune deficiency syndrome, is a set of symptoms and infections that develop from damage to the immune system. The prevailing belief is that Aids is caused by the human immunodeficiency virus, or HIV, as it is commonly referred to (Aids Foundation South Africa, n.d., Frequently asked questions).

Since the identification of Aids in the mid-1980s the virus, which is believed to have originated in central Africa, has spread to all corners of the earth. The first known cases of HIV infection emerged in 1982 amongst the gay population. Today it is believed that more than 39.5 million people across the world are infected with the virus and an estimated 24.7 million of these cases are found in sub-Saharan Africa. However, it is South Africa which has the highest HIV infection rate in the world (Youde, 2007). Currently it is believed that over 5 million adults in South Africa are HIV positive (Youde, 2007). With reference to this statistic, UNAIDS (as cited in Squire, 2007, p. 1) claims that "the country's AIDS epidemic – 'one of the worst in the world – shows no evidence of a decline'".

Frey, Adelman, and Query (1996) give three definitions of HIV/Aids. Firstly, the general understanding of HIV/Aids, termed the *physical perspective*, locates health or illness within the body of the individual. This is according to the medical model. The second interpretation of health, the *psychological perspective*, focuses on the subjective experience of health, and locates illness within the individual. According to Frey et al. (1996), a third meaning of health can be identified, namely the *cultural perspective*. This, they argue, shifts the focus of health and illness from existing within the individual to the collective level and thereby connects these notions to societal beliefs, values and practices. Rosenberg (as cited in Herek, Capitanio, & Widaman, 2003, p. 533) concurs and states, "A disease is no absolute physical entity but a complex intellectual construct, an amalgam of biological state and social definition". When applied to HIV/Aids this expands the notion of illness and leads to a more encompassing description, such as the one supplied by Cameron (2005). He contends that "AIDS is a disease. It is an infection, a syndrome, an illness, a disorder, a condition threatening to human life. It is an epidemic – a social crisis, an economic catastrophe, a political challenge, a human disaster" (Cameron, 2005, p. 42).

The Changing Face of HIV/Aids

A "New" Disease is "Discovered"

It is believed that the first cases of HIV occurred as early as the 1930s; however, it was not until the 1980s that there was public testimony to the disease (Whiteside, 2008). Aetiological evidence points to Africa as the place of origin, where the disease made the leap from primates to humans. In South Africa the first case of HIV was reported in 1982, and thereafter an increasing number of cases came to the fore. The emergence of HIV/Aids shook the very fabric of human existence because Aids exposed "some of humanity's worst fears and prejudices...AIDS forces us to face up to many taboo subjects like sex, death, promiscuity, homosexuality and drug abuse" (Van der Walt & McKay, as cited in De Jongh van Arkel, 1991, p. 45).

During this time the demography of infected individuals included predominantly homosexual men, and HIV/Aids was framed as a white, gay, male disease; a disease of drug users and of homosexuals (Squire, 2007). Social discourse at this time emerged from the considerable misunderstandings and fear associated with the disease (Miller, 1987). In 1987 Miller pointed out that HIV/Aids "is still widely regarded as a 'gay' disease, and stereotyping...and prejudice...have stood in the way of greater social understanding" (p. ix).

However, it was not long until the heterosexual infection rate overtook that of homosexual infections in South Africa, and HIV/Aids became a reality which invaded all segments of the population. During this period anti-apartheid activists, as well as gay and lesbian activists, campaigned to increase awareness of the disease and demanded government intervention. Regardless of this ongoing quest for increased knowledge and understanding of the disease and its effects, beliefs about the disease were tarnished by a growing stigmatisation and discrimination against those infected (Squire, 2007).

The Pendulum Swings Towards an African Definition

Squire (2007) marks the death of Aids activist Gugu Dlamini, who was beaten to death by community members after disclosing her HIV status in 1998, as a turning point towards the acceptance of HIV infected individuals. However, social discourse about HIV/Aids in South Africa remained riddled with ambiguity.

At this time, HIV/Aids had alarmingly rapid infection rates, and in the absence of a cure or any reliable form of treatment, this resulted in a common understanding of HIV/Aids as meaning an early death (Carricaburu & Pierret, as cited in Pierret, 2007). A fundamental shift in thinking emerged in the West by the late 1990s, primarily owing to the dramatic advances in the treatment of HIV/Aids, known as HAART or highly active antiretroviral therapy. HAART had a fundamental impact because not only did it play a role in increasing the life expectancy of HIV positive individuals significantly, but the onset of full-blown AIDS could now also be significantly delayed (Pierret, 2007). “More recently, HIV therapies have advanced considerably resulting in individuals failing to exhibit a standard pattern of declining health...HIV is now considered a chronic yet manageable disease" (Serovich, Craft, & Yoon, 2007, p. 971).

Although the advancement in treatment has been significant in the fight against HIV/Aids, thus far its impact in Africa and in South Africa has been less marked than in the West. Downing (2005) writes extensively about this issue. He argues that African discourse on HIV/Aids is inherently different from that of the West and hence the fight against the disease also differs significantly. The cornerstone of his debate is the extent to which he believes Mbeki was misunderstood by the West, in regard to his "controversial" descriptions of the disease in Africa. According to Downing, Mbeki believed HAART to be extremely expensive and that its widespread use in Africa was questionable. He (Downing, 2005, p. 67) describes his understanding of Mbeki's point of view as follows:

> Likely, instead of having no philosophy of disease and treatment, he had an African philosophy deeply rooted in his consciousness. And likely, when he saw the responses of the scientific community to the AIDS epidemic, he felt dissonance with his African understanding.

According to Youde (2007), "no single person has influenced the discourse of AIDS in Africa as much as Thabo Mbeki" (p. 58). Mbeki's philosophy on HIV/Aids (Downing, 2005) was in line with the unique patterns he witnessed in Africa, which are not the same as those in the Western world. Mbeki maintained that HIV/Aids in Africa was predominantly heterosexually transmitted, it had taken on epidemic proportions as millions of people had died, and HIV related deaths were not declining as increasing numbers of Africans were becoming infected. He argued that HIV/Aids could not be viewed with the same lens in Africa as the one used in the West (Downing, 2005).

Furthermore, Mbeki was of the opinion that HIV/Aids in Africa had to be understood within the broader social context, and aspects such as the environment and poverty could not be overlooked or ignored as contributing factors (Downing, 2005). Duffy (2005) concurs, indicating that no discussion of HIV/Aids in Africa is complete without including the level of poverty and suffering that exists in areas with high HIV prevalence. Lock (as cited in Duffy, 2005) states that "efforts to reduce suffering have habitually focused on control and repair of individual bodies...the social origins of suffering and distress, including poverty and discrimination...are set aside" (p. 19). What the above positions illustrate is how social discourse has been shaped in the African and South African contexts, and they highlight some of the difficulties that feed the ongoing ambiguity in the South African understanding and definition of HIV/Aids.

The array of descriptions, meanings, experiences and discourses about HIV/Aids is evident in the large body of research available. It is important at this stage to highlight that much of the research deals with how stigmatisation and discrimination affect social discourse on HIV/Aids, which is discussed below. Moreover, there is an acknowledgement of the different ways in which HIV/Aids is conceptualised today, including how it is viewed in the West on the one hand and in Africa on the other. One example of such research is by Downing (2005), who writes that the West "doesn't seem to realise that there are African discourses of AIDS fundamentally different from the Western discourses" (p. 29). However, views and beliefs are not restricted to Western versus African understandings. Just as HIV/Aids is conceptualised differently in the West and in Africa, based on the vastly differing socio-cultural contexts, so too within South Africa there are many descriptions and definitions of HIV/Aids, which contribute to social discourse on how HIV/Aids is ultimately understood.

Social Discourse and HIV/Aids

In this section the impact of the underlying cultural epistemology of Africans and South Africans, which allows for particular discourses of this disease to emerge, will be considered.

Frey et al. (1996) point out that although the physical, psychological and societal meanings form different points of entry to understanding HIV/Aids, these do not stand in isolation but are intricately intertwined. They note, “Communication is a connecting thread that weaves together these different layers of meanings regarding health, and moves us beyond dualistic choices” (p. 386). They further argue that meanings of health and illness become defined through the numerous communication practices that characterise social life. From this perspective, HIV/Aids is defined and understood as being constructed through “the communication patterns that characterize the social relations within which a person is embedded” (p. 387).

Similarly, Bethel (1995) argues that HIV/Aids has been transformed into a culturally constructed illness. The notion of HIV/Aids, she believes, comprises two main components. On the one hand it is a medical condition, a disease, which presents in particular ways and for which there are certain treatments; and on the other hand it is a culturally constructed illness, because it “is perceived, understood, and acted upon (or not acted upon) within a framework of culturally derived meanings” (Bethel, 1995, p. 24). From this perspective, the disease cannot be separated from the cultural meanings that have created particular conceptualisations of the illness. In this regard Bethel (1995, p. 5) states:

> The ecology of HIV/AIDS has both a physical and a cultural dimension, and an understanding of the physical is simply not possible without an understanding of the

> cultural factors that have shaped the trajectory as well as the perceptions of the epidemic.

Cultural discourse regarding HIV/Aids is of particular significance in a country like South Africa that houses vastly different cultural belief systems. Van Niekerk (1991) contends that HIV/Aids is not only a social disease in South Africa, but a political one as well. He points out how the underlying societal discourse of racism, for example, can affect ideas and beliefs about HIV/Aids. Campbell, Nair, Maimane, and Nicholson (2007) concur, using an example of a young black man in a rural community who believes that the HI virus was implanted into condoms and that this was the result of "malicious supporters of the old apartheid regime seeking to kill black South Africans" (p. 408). Van Niekerk (1991) also emphasises the effect of traditionally entrenched attitudes regarding issues such as sex, sex education and disease, and the implications of these on perceptions of the disease. One significant way that these beliefs inform discourse about HIV/Aids is seen in the emergence of specific HIV/Aids related stigmas.

Campbell et al. (2007) highlight six core influences of stigmatisation in the South African context, namely "fear; availability/relevance of information; lack of social spaces to talk about HIV/Aids; sexual moralities and power relations; the lack of adequate HIV/Aids prevention and treatment services; and poverty" (p. 406). These, they believe, allow for a more multidimensional view, which incorporates unconscious, community and macro-social issues. In this regard, they point out that popular discourse regarding HIV/Aids is often contradicted by "traditional African cosmology", which has implications for the individual's thinking and behaviours (p. 408). One example they highlight in their study is the difficulty some people have in acting on HIV/Aids information because it directly opposes other fundamental beliefs that are held within their particular culture. They specify an example of such a belief within traditional African cosmology, which is that HIV/Aids is caused by witchcraft, more specifically, “by the bewitching of the sufferer by someone who is jealous of them” (Campbell et al., 2007, p. 409). In this regard Bethel (1995) argues that “biological and medical ‘facts’ about the virus have often been blurred by cultural mythologies” (p. 5).

What this illustrates is that the definition of HIV/Aids in South Africa is complex, as it arises from varying vantage points and belief systems about health and illness. Therefore, in order to furnish a comprehensive understanding of the impact of cultural beliefs on the social definition of HIV/Aids, a deeper look at the meanings of illness and well being is required.

Meanings of Health and Illness

“In every culture explanations of illness are dependent on the overall world-view adhered to in that culture” (Snyman, 1998, p. 186). In South Africa, such explanations do not arise from a single vantage point; rather, it can be argued that current discourse regarding health and illness is underpinned by both Western and African philosophies.

Kaphagawani and Malherbe (as cited in Coetzee & Roux, 1998) argue for the existence of an African epistemology. They highlight that all humans have the capacity for knowledge, regardless of race, culture or tribe. Therefore epistemology as the study of claims of knowledge is universal. However, they point out that “the ways of acquiring knowledge vary according to the socio-cultural contexts within which knowledge claims are formulated and articulated” (Kaphagawani & Malherbe, as cited in Coetzee & Roux, 1998, p. 206). They believe that it is possible to conceptualise of both an African and a Western epistemology.

Hence one can conceptualise of both an African and a Western understanding of illness. This line of thinking allows for an understanding of how the meanings of HIV/Aids can differ profoundly from one culture to the next, and hence, how in South Africa conceptualising HIV/Aids will have elements of both its cultural roots.

Van der Walt and McKay (as cited in De Jongh van Arkel, 1991, p. 45) point out that "AIDS...highlights the basic dualism which pervades much of Western thinking: there are sick people and well people; there are bad people and good people; there is proper behaviour and improper behaviour". This illustrates the way in which a Western perspective of illness shapes a particular description of HIV/Aids. Conversely, Snyman (1998, p. 186) states:

> From an African perspective the cosmos is holistic and spiritual, and the individual, as well as his/her experiences and life, can consequently only be understood from the vantage point of community and religion. Similarly, the notions of health, well being and illness, both physical and psychological, need to be understood within these parameters.

Okwu (as cited in Snyman, 1998) believes that in Africa illness is widely conceived of as the direct result of supernatural forces. More specifically, illness may well result from witchcraft or magic that is used by one individual to punish another, which is achieved through the aid of supernatural forces (Okwu, as cited in Snyman, 1998). Kalichman and Simbayi (2004) examined belief systems amongst South African sub-cultures who believe that HIV/Aids is caused by supernatural forces and spirits. Their research highlights an association between such belief systems and HIV/Aids related stigmatisation, which they found significantly impedes HIV/Aids counselling, testing and prevention efforts, and further entrenches HIV/Aids stigmas. They also indicate that traditional belief systems of health and illness point to ancestors and God as the primary causes of illness. Hence HIV/Aids can be understood as the consequence of angering the ancestors or God. Kalichman and Simbayi (2004) attest that such thinking underpins HIV/Aids related stigmatisation because of the belief that the illness is brought onto the individual, and as such onto the entire community, by himself or herself.

The effect of witchcraft, seen from a non-African view, is illustrated in research done by Walker, Reid, and Cornell (2004). They argue that “witchcraft interpretations of HIV/AIDS can have an extremely negative impact” (p. 100). One example they provide is the stigma that is associated with witchcraft, which in turn perpetuates the cycle of silence already surrounding the illness. This, they believe, further entrenches HIV/Aids related stigmas and impedes efforts to encourage acceptance of HIV positive individuals into families and communities (Walker, Reid, & Cornell, 2004).

An Epidemic of Stigma

The connection between stigmatisation and discrimination underpins community attitudes, belief systems and social discourse, and hence notions of HIV/Aids. As a result, a great deal of research has focused on the effects of prejudices surrounding HIV/Aids and the stigmatisation and discrimination that emerge as a result of social discourse.

In accordance with Frey et al. (1996) and Bethel (1995) mentioned above, Herek et al. (2003) perceive HIV/Aids to be a social illness. They point out that the social nature of illness, specifically with regard to HIV/Aids, is particularly evident in the stigmatisation, social ostracism and discrimination that occurs. Such stigmatisation, they argue, can either be amplified or it can protect its victims, depending on social health policy. In this regard, Burris (as cited in Herek et al., 2003) introduces the concept *social risk*, which refers to the possibility that a person may be socially penalised if they become infected with a feared and indigent disease. This, they argue, leads to *felt stigma*, or the shame and fear of discrimination. Herek et al. (2003) further note that these constructs illustrate the fundamental role played by the social climate in identifying options available to people with stigmatised illnesses such as HIV/Aids. They also point out that for the ill person "social risk and felt stigma are heightened to the extent that stigma is perceived to be widespread" (p. 534).

In order to appreciate the impact of stigma in South Africa, Kalichman et al. (2005) developed a brief scale to measure Aids-related stigma. They point to previous research in South Africa, which looks at the impact of stigma at two levels: Firstly, at a societal level where stigma is seen as directly affecting and undermining public support for programmes that aid HIV positive individuals in society; secondly, at individual level where stigma creates an obstacle to prevention, testing and care for HIV positive individuals. The findings from the brief scale confirmed these suggestions. It was found that one fifth of the sample felt that "people with AIDS cannot be trusted, should feel guilty, and should not be allowed to work with children" (Kalichman et al., 2005, p. 135). In interviews with health workers in South Africa, they further found that stigma poses a barrier to HIV prevention methods and counselling, and that it is the most significant factor attributed to community members not testing for HIV. Kalichman et al. (2005) report that "Aids related stigma was viewed as the most pressing social aspect of HIV/AIDS" (p. 137). In Kenya, Hamra, Ross, Karuri, Orrs, and D'Agostino (2005) developed a similar Aids related stigma scale, which takes into account the impact of specific beliefs and knowledge about the care of people (children in particular) living with HIV, and the association of these beliefs and knowledge with expressed stigma. They identified a significant relationship between care and support, and expressed stigma within this community.

Campbell et al. (2007) support the notion that the HIV/Aids stigma is derived from a complex interplay of psychological and social factors. They define stigma as “any negative thoughts, feelings or actions towards people infected with HIV or living with Aids” (p. 404). They found that while previous research focused on individual aspects such as lack of knowledge or attitudes, it failed to include the fundamental influence that societal aspects had on these individual phenomena. Their research thus focuses on understanding why certain groups become stigmatised, at certain times, and in specific contexts. This, they explain, entails a deeper comprehension of the “types of societal forces that become sedimented in people’s inner experiences at particular times and places” (p. 404).

Hergovich, Ratky, and Stollreiter (2003) conducted a study to investigate the impact of cultural attitudes on HIV/Aids. They examined the connection between societal beliefs in a just world, sexual morality and values, and their effect on attitudes and prejudices towards HIV positive individuals. They attribute the negative attitudes and stigmatisation of those infected with HIV/Aids to an underlying societal discourse that attests that the disease is associated with “promiscuity, drugs, homosexuality and death” (p. 37). They also point out that there is a connection between society’s belief in a just world on the one hand and such attitudes on the other, because “people like to believe that everyone gets what they deserve”. This in turn is underpinned by the “human need to keep up the illusion of a well-ordered and secure environment” (Hergovich et al., 2003, p. 38).

Social Discourse and the Self

One way in which to understand stigmatisation is by looking at the role of the attribution of labels to those infected with HIV/Aids. Such labels “define the social group by projecting its negative values on the other who is labelled defective” (Kleinman, as cited in Duffy, 2005, p. 15). In an attempt to understand the origins of stigmatisation, Duffy (2005) refers to Goffman (1963), who is described as a pioneer in the relationship between stigma and disease progression. According to Goffman, an individual who is marked as different is “reduced in our minds from a whole and usual person to a tainted, discounted one” (as cited in Duffy, 2005, p. 14). Duffy further explains that stigmatisation reduces the HIV positive individual to a substandard level, to “not quite human”, which results in him or her being a soft target for discrimination (p. 14).

Kleinman (as cited in Duffy, 2005) adds another dimension that emphasises the notion of “other”, namely the physical disfigurations of some individuals suffering from Aids. He argues that stigmatisation also occurs as a result of the fact that individuals with Aids “break cultural conventions about what is acceptable appearance and behaviour, while invoking other cultural categories – of what is ugly, feared, alien, or inhuman” (Kleinman, as cited in Duffy, 2005, p.15). Lastly, Kleinman notes that a further explanation for stigmatisation resides in the moral and religious belief that holds that certain individuals are deemed evil or sinful.

Duffy (2005) highlights the importance of social discourse and public response, in how individuals within a society view themselves, and how this in turn shapes their “social identity” (p. 15). Kleinman (as cited in Duffy, 2005, p. 15) explains how “the stigmatisation process usually begins with the community’s response to the person, but eventually the person ‘comes to expect such reactions, to anticipate them before they occur and even when they don’t occur’”. The socially created HIV identity is thus incorporated into the HIV positive individuals’ descriptions and conceptualisations of self. Furthermore, social discourse is shaped by the distinctions that are drawn between self and other. This notion is often extended to marginalise entire families, rather than merely labelling the infected person.

An “AIDS Family”

Iwelinmor, Airhihenbuwa, Okoror, Brown, and BeLue (2008) point out that “HIV/AIDS in sub-Saharan Africa has grown to become an epidemic that affects the family as a functioning system, threatening its supportive capacity, and redefining the manner of coping and adapting to the burden of disease” (p. 322).

The effects of the illness on the family encompass various aspects. For example, HIV/Aids brings with it the burden of additional economic hardship; it also disrupts the family in its ability to care for the infected member/s. Iwelinmor et al. (2008) attribute this largely to feelings such as “fear, anger, shame, sadness, uncertainty of the illness process, and stigma associated with the disease”, which they believe leads to “social isolation and loneliness” for the HIV positive individual and the close family members (p. 323). They emphasise that HIV/Aids has become a multifaceted and collective experience, one that is shared by families and communities (Iwelinmor et al., 2008). It is therefore the whole family, rather than merely the individual, who is affected and labelled.

Alubo et al. (as cited in Iwelinmor et al., 2008) found that in certain Nigerian communities the family of an HIV positive individual becomes commonly known as an “AIDS family” by other villagers (p. 323). In their research of family oriented communities, Sun et al. (2007) had similar findings. They point out that although stigma is a dominant issue in all cultures, it is significantly more powerful in family oriented societies. In such societies “HIV-related stigma is borne not only by the individuals but also by the family and community” (Sun et al., 2007, p. 308). What the above research fundamentally illustrates is that HIV/Aids is not something that exists within an individual alone; it has a profoundly relational aspect, and affects individuals, families and entire communities.

Disclosure

Disclosure is a critical aspect of living with HIV/Aids because it is not only fundamental to those living with the disease, but is also “inexorably linked to issues of support juxtaposed with stigma” (Paxton, as cited in Emlet, 2008, p. 711). The infected individual thus faces a paradoxical decision because “while disclosure is a prerequisite for acquiring social support, it opens up the potential for stigma and the shame of having HIV” (Emlet, 2008, p. 711).

Campbell et al. (2007) point out the effect of stigmatisation and discrimination with regard to disclosure. This, they believe, manifests in the way it is further perpetuated within families, is supported by various forms of denial, undermines prevention and care strategies and has adverse effects on social support networks. A paper by Derlega, Winstead, Greene, Serovich, and Elwood (2002) focuses on the specific effects of stigmatisation on disclosure. They examined the extent to which perceived HIV-related stigma impacts on the individual’s motivations for and against HIV disclosure, and found that this was strongly related to perceptions of rejection. Draimin (as cited in Ostrom, Serovich, Lim, & Mason, 2006) maintains that an individual’s struggle to disclose to their family can be attributed to the attainment of “emotional or instrumental support” on the one hand, versus being subjected to rejection on the other (p. 60).

Theories of Disclosure

Disease progression theory.

The disease progression theory of HIV/Aids disclosure holds that individuals disclose their status only when they become symptomatic (Serovich, Lim, & Mason, 2008). It is thought that this is predominantly because as the illness progresses to full-blown Aids it is no longer possible to hide one’s status. They point to numerous reasons why this is the case, for example: Disease progression leads to hospitalisation, physical signs and symptoms begin to appear and at a psychological level, because death is imminent, individuals’ need for support increases (Serovich et al., 2008).

Serovich et al. (2008) investigated this theory amongst women in the USA and found that although previous research pointed to disease progression theory as a dominant factor indicating disclosure, “advanced therapies have changed the progression of HIV, with many women living longer, healthier, and more productive lives” (p. 28). Furthermore, the advancement of therapies has resulted in a failure of many individuals who are infected, to present with a pattern of deteriorating health (Serovich, Craft, & Yoon, 2007). Serovich et al. (2008) further point out that as societies become more educated and accepting of individuals with HIV/Aids, the probable rewards of disclosure could outweigh any negative implications (Serovich et al., 2008).

Disease consequence theory.

The findings by Serovich et al. (2008) also support the consequence theory of disclosure. Consequence theory suggests that "disease progression influences disclosure through individuals' perception of the consequences anticipated as a result of disclosure" (Serovich, in Serovich et al., 2008, p. 24). The individual is therefore faced with a cost-reward analysis (Emlet, 2008). Research has shown that once the perceived rewards of disclosure outweigh the costs, individuals are far more likely to disclose their HIV status. These rewards include acquiring physical, social and emotional support, as well as relief after sharing an arduous secret (Serovich et al., 2008). Similar results emerged from research done by Emlet (2008), who studied disclosure patterns of older adults, aged 50-72. He found that disclosure amongst this sector of the population is extremely limited, although some individuals do disclose. However, in these instances the pros and cons of disclosure to family and friends are weighed up before disclosure occurs (Emlet, 2008).

Reasons For and Against Disclosure

Norman, Chopra, and Kadiyala (2007) conducted research on disclosure in two South African communities. Disclosure, they reason, is fundamental in these contexts because it is the "catalyst for access to a variety of important and often essential recourses", such as the establishment of family and/or community support networks (Norman et al., 2007, p. 1775). They add that disclosure has significant implications for how HIV positive individuals respond to the impact of HIV/Aids in all aspects of their lives. They found that the perception of real stigma and fear of discrimination are significant factors, and that these, as well as other factors, influence the process of cost-benefit analysis that precedes disclosure. This leans toward the consequence theory of disclosure. However, further findings suggest that the process of disclosure is also greatly influenced by the broader social and political contexts, including socio-political activism and HIV/Aids movements. This improves the rational potential benefits of disclosure, and therefore impacts the reasons for disclosure (Norman et al., 2007). Norman et al. (2007) thus identify both the consequence theory and the moral economic approach as mutually influential aspects of disclosure in the South African context.

In his research on disclosure amongst the older population, Emlet (2008) found certain patterns and themes evident with regard to disclosure. He confirmed previous statistics that indicated that disclosure amongst the adult population is minimal. However, his findings indicate that the disclosure patterns and reasons for and against disclosure for the older age group are similar to those of younger people (Emlet, 2008). In this study, patterns emerged that highlight various prominent themes which link to individuals' reasons for disclosure or non-disclosure. What Emlet (2008) found was that those who did not disclose their status did so because of three factors: Firstly, *protective silence*, which stems from fears of rejection and stigmatisation, and involves a personal component of privacy – that it was their business alone; secondly, *anticipatory disclosure*, involving the internal process of weighing up the pros and cons of disclosure; and thirdly, *violations of confidentiality*, which involves unauthorised disclosure by another. The themes of those who choose to disclose their status include *unintentional disclosure* and *intentional disclosure*. Although individuals experienced anxieties and fears about the possibility of *unintentional disclosure*, the findings suggest that even though not all disclosure is voluntary, it is not necessarily as dramatic as a violation of confidentiality, where in certain cases the likely benefits are contemplated. *Intentional disclosure* encompasses all of the above themes as these individuals were found to have contemplated all the possible factors and implications. The reasons for disclosure, furthermore, varied and included aspects such as honesty, openness, as well as the desire to educate and to promote prevention (Emlet, 2008).

Disclosure in the Context of Relationship

Serovich et al. (2008) review research that has been conducted on disclosure to family and friends, and highlight certain contradictory findings, which indicate that while some argue that family members are disclosed to most often, others indicate that it is lovers and friends who are most often told. In this regard, research by Serovich, Esbensen, and Mason (2007) concluded that HIV disclosure is considerably higher to friends than it is to family, particularly with regard to homosexual men. Regardless of the research findings being inconclusive, they do highlight the importance of the decision to disclose and the effects of disclosure within close and familial relationships for the infected person. Furthermore, it is indicated that the decision to disclose is complex and significant in that it has an impact on many aspects of the individual’s ongoing journey with HIV/Aids.

Decisions regarding disclosure play a significant role in essential domains, such as the individual’s physical and mental health, access to social support and even risk of further transmission. In turn, these factors influence the psychosocial coping ability of the HIV positive individual. Sun et al. (2007) note that disclosure to family in particular can have a significant impact on the individual's internal psychological process, because it may elicit fear, shame or stress, all of which may lead to isolation. Ostrom et al. (2006) point out a further issue about disclosure of HIV status within families, namely the issue of trust. Murphy et al. (as cited in Ostrom et al., 2006) highlight the fact that disclosure on any level places the individual at risk for further disclosure, which in turn increases his/her vulnerability.

Disclosure and Personal Identity

In contrast to previous studies, which evaluated HIV disclosure in the context of relationships, Arnold, Rice, Flannery, and Rotheram-Borus (2007) attempt to understand disclosure in terms of personal identity. They look at how disclosure fits into the personal and social identity of the infected person. The classification of HIV as a chronic disease impacts the notion of disclosure because it is a "lifelong challenge that impacts adjustment" (Arnold et al., 2007, p. 87). Moreover, Arnold et al. (2007, p. 87) state that:

> This focus obscures the underlying reality that any given act of disclosure is embedded in the process of ongoing social interactions over time. It is important to conceive of disclosure as an ongoing social and psychological process of communication about critical health information.

Arnold et al. (2007) believe that the process of disclosure differs from person to person and highlight three prominent pathways to disclosure, which all have different implications for identity. *Disclosure to everyone* makes the individual's HIV status a central attribute of his or her personal identity and involves simple coping styles and problem solving skills. *Disclosure to no one* calls for the employment of strategies for securing social support, while ensuring anonymity. This is the simplest pathway as it requires simple coping skills and no active problem solving. Lastly, *disclosure to some* requires very strategic decisions. Arnold et al. (2007) argue that this is the most common and most complex choice, because the individual is required to be proactive and endure constant decisions as well as having to employ rigorous problem solving strategies. Arnold et al. (2007) describe previous studies on disclosure as having focused only on “isolated behaviour engaged in with specific persons”, whereas their research points to disclosure as a “reflection of a cohesive, integrated set of social identities and role relationships that affect decision rules” (p. 91).

It is evident from the above that individual reasons for disclosure, as well as the decision of who to disclose to differ significantly from one person to another. However, what is irrefutable is the extent to which society impacts whether or not someone will disclose, and the vast consequences of disclosure or not on the HIV positive individual.

Living with HIV/Aids

In conclusion, a brief description of three unique stories of individuals living with HIV/Aids in South Africa brings to life the ideas and issues that have been discussed in this section.

Adam Levin

Levin’s memoirs of living with HIV/Aids (2005) is a description of his personal story of living with this disease. It is an emotional and brutally honest tale of his gruelling battle with the illness. He discusses in detail his journey in a society where discrimination and stigma regarding HIV/Aids are commonplace, and where secrecy, silence and ignorance still exist about the disease. He powerfully states that “Aids never strikes in isolation. It strikes in a context of economies and infrastructure and belief systems. And most often it is that context rather than the disease itself that determines one’s chance of survival” (p. 76).

Levin remembers that when he was first diagnosed, he was desperate for information and answers, but found none. He believes, “In its own insidious way, the conspiracy to keep this disease walled in silence had triumphed” (Levin, 2005, p. x). The silence of Aids was not only evident in how the disease was ‘contained’ within South Africa, but is also weaved throughout his personal struggle. However, his journey thus far is not one of isolation. His solitary struggle is continually juxtaposed against the immense support he received from his parents and from a few close friends. Unlike so many, Levin disclosed his HIV status to his parents on the same day he found out he was HIV positive, and found overwhelming support. He remembers, “There’s no hint of judgement. No blame...For so many people, this moment marks the opening of a vast rift, an onslaught of stigmas and embarrassment” (p. 17).

His journey highlights the fight and struggle for survival that HIV positive individuals endure and what it takes to keep the disease at bay. But it also emphasises the vastly different and individual processes that each HIV positive person’s journey encompasses. He explains how he made peace with his own struggle: “What matters is a subtle but fundamental shift inside me – for, in making this decision, I absolve myself of any trace of guilt or regret...I must accept everything that has happened and everything that is still to come” (Levin, 2005, p. 229).

Edwin Cameron

Cameron's measured and more academic account (2005) of living with HIV focuses on his own struggle, which he contextualises by placing it in the broader social context of the epidemic in South Africa. This account highlights the sombre realities that individuals who are HIV positive face in South Africa today – it is a personal psychological reality that is informed by communal societal discourse about HIV/Aids. He points to notions of individual survival and explains the harsh realities of stigmatisation about the disease as follows: "It lies in the fears and self-loathing, the self-undermining and ultimately self-destroying inner sense of self-blame that all too many people living with AIDS experience" (Cameron, 2005, p. 53).

Cameron looks at some of the controversial silenced issues that exist in our communities, which HIV/Aids has forcibly uncovered. He writes, "The epidemic's proximities and juxtapositions have brought the inequalities of the developed and developing world closer than comfort can warrant" (p. 211). He points to how the epidemic has uncovered social divides between rich and poor, between Africa and the West and furthermore, how it has demanded a closer inspection of the unspoken issues facing South Africa, such as the impact of poverty and apartheid. But most significantly he describes the fear with which society deals with HIV/Aids. In this regard he writes that "We have responded to the epidemic with silence; and our doing so has rendered it and those who suffer under it unspeakable" (Cameron, 2005, p. 213).

However, amidst these harsh realities, Cameron writes about his personal triumphs over the illness. He says, "I know I have AIDS...and yet my days also have sun and food and energy and fun and work and friendship and family and hope and challenge and belief and happiness" (p. 214). He encourages people to push the boundaries of their humanity, to fight this disease together. They should not be crippled by the loss already experienced, or by the fear about the disease, but should use the grief, fear and bereavement and turn it into an energy for living, as he has done.

Fana Khaba

The story of the life and death of Khaba or Khabzela, as the late DJ was known, is told by McGregor (2005). In this account of his journey, she uncovers the paradoxes of the connections between Khabzela's struggle with the disease, and the country in which he lived, South Africa. She also exposes the tragedy of the millions of lives that are not saved and could be prolonged through education and medication, through his story. She writes (McGregor, 2005, p. ix):

> Khabzela's premature death was all the more tragic because it was preventable. Unlike millions of other people with Aids, he was offered the drugs that might have given him another twenty –odd years of healthy life – possibly until a cure was found. But he refused to take them.

The paradox in Khabzela's story is that on the one hand he was a well-educated and "modern man", who lived in urban areas. But despite this Western context he rejected mainstream views on HIV/Aids for a more indigenous description. He attributed his HIV infection to having been bewitched and he was distrustful of Western medicine. Within the vastness of South African cultures, he was not alone in his beliefs. His story deconstructs the complex interplay of the varying belief systems and understandings of HIV/Aids in South Africa. McGregor (2005) concludes that the journey through Khabzela's life was a profound learning as she realised the complexities of South Africans' responses to HIV/Aids.

Conclusion

It is evident from the above research that HIV/Aids is much more than a disease. It is a multifaceted phenomenon that has permeated all aspects of society. It is clear that HIV/Aids is a hugely complex issue in South Africa, and in the world, as its devastating effects escalate. Furthermore, the research points to vastly different understandings of the illness, which are continually evolving, and which are underpinned to a large extent by the social discourses of the time and the contexts in which these understandings emerge. This is particularly relevant in South Africa, where beliefs about the illness still vary owing to many cultural belief systems and the politics of HIV/Aids in this country. As a result it can be argued that there is a uniquely South African understanding of HIV/Aids, which is a product of the blend of various social discourses. This in turn informs and shapes our experiences and belief systems about the illness, which profoundly reverberate onto those who are HIV positive.

It has also been shown that the resulting stigmatisation and discrimination, which emerge from societal discourse, have profound implications for HIV positive individuals, as they affect every facet of their daily lives, choices, relationships and even their sense of self. Further to this, the research has shown that HIV/Aids should be understood as existing not only within individuals, but in relationships and in families.

The significance of disclosure is also highlighted in the vast body of research on HIV/Aids. The infected individual gruellingly weighs up the pros and cons of disclosure, because it informs many aspects of their journey, such as whether their experiences will be ones of solitude or connectedness, whether they will face rejection or gain acceptance, or if they will be supported or suffer alone. This is more critical today than ever before because “HIV has become a disease to live with rather than to die from” (Rosenberg, as cited in Serovich et al., 2008, p. 23).

In the following chapter, the above literature, the research approach and the research findings will be contextualised within the postmodern framework and the social constructionist perspective, in order to develop a methodology for the research.

CHAPTER 3

METHODOLOGY: A SINGLE CASE STUDY

In the previous chapter the evolving layers of meaning regarding HIV/Aids in South Africa were described. As mentioned, the aim of this research is to deconstruct the layers of meaning that one man has created regarding his life with HIV. Such a construction of meaning and the process of deconstruction fit in with the social constructionist paradigm. In the following paragraphs social constructionism will be described and placed within the postmodern framework. Furthermore, as this research focuses on one man’s story, told against the background of a socially constructed reality, the story will be anchored in narrative theory. The various aspects of the research design will then be addressed, with reference to the qualitative research method and the single case study approach.

Ontology, Epistemology, Paradigm and Theory

Postmodernism

Ontology is a description of the nature of the world as it is (Held & Pols, 1985). It describes the concepts and facts held about existence which constitute the general *Weltanschauung* of a time or era. The modernist world view was built on the laws of mechanics, science and mathematics, and knowledge was communicated through these languages (Becvar & Becvar, 2006). The cornerstones of modernism are therefore the notions of universal truths, linear cause and effect, the conceptions of the world as understandable, measurable, predictable and quantifiable (Fuks, 1998), and the belief in objective knowledge. Knowledge was thus seen as something that existed “out there” and could be attained objectively through a specific scientific method. This promise of objective knowledge resulted in a “belief of human capacities for reason and observation, prediction and control” (Gergen, 1992, p. 52).

According to Capra (1983) new concepts which developed in physics at the beginning of the 20th century spearheaded a challenge and questioning of modernist thinking. This resulted in a shift in the Western world view in the second half of the previous century, from a mechanistic or modernistic perspective toward a more holistic and ecological view. This paradigm shift has brought about what many refer to as the postmodern era. Capra (1983, p. 32) argues that,

> The universe is no longer seen as a machine, made up of a multitude of separate objects, but appears as a harmonious invisible whole: a network of dynamic relationships that include the human observer and his or her consciousness in an essential way.

It is important to note that modernist explanations of the world and reality are not entirely disregarded but are deemed as being one version of the truth, because in the postmodern era the world view is that there are many possible interpretations or truths (Becvar & Becvar, 2006).

Postmodernism is characterised by a move away from universal and objective knowledge toward a more socially useful, local, subjective knowledge (Kvale, 1992). Knowledge and reality are no longer viewed as existing externally to the individual but rather are understood as being created by language, beliefs, values and the contexts or societies in which we live (Lynch, 1997). It is through language and conversation, within a given context, that we acquire and comprehend knowledge. Kvale (1992) postulates that “postmodern thought is characterised by a loss of belief in an objective world and an incredulity towards meta-narratives of legitimation” (p. 32). Therefore, there is a shift in focus toward a social and linguistic construction of reality. Individuals come to know and understand their worlds through language. From the postmodern perspective, the researcher endeavours to “deconstruct ‘facts’ by delineating the assumptions, values, and ideologies on which they rest” (Becvar & Becvar, 2006, p. 93).

Finally, in the postmodern era, the modernist notion of “the dichotomy of universal societal laws and the individual self are replaced by the interaction of local networks” (Kvale, 1992, p. 3). Therefore, it is a move toward a relational rather than an individualised notion of self. Furthermore, the self is not an isolated autonomous being, but conversely is viewed as being constructed in relationship (Becvar & Becvar, 2006).

Constructivism and Social Constructionism

Constructivism.

Held and Pols (1985) broadly define an epistemology as the study of the nature of knowledge, what knowledge is and our various claims to knowledge. Anderson (1997) contends that constructivism is an epistemology, because it is a “philosophical theory of knowledge” (p. 23). The constructivist perspective rests on the premise that “in the process of perceiving and describing experience, whether to ourselves or to others, we construct not only our personal knowledge base about reality but also our reality itself” (Becvar & Becvar, 2006, p. 91). Every observation is therefore a construction; our worlds are constructed and not discovered; we "bring forth" what we see (Maturana, as cited in Anderson, 1997, p. 23). Constructivism is therefore inherently postmodern, because it emulates one of the most predominant premises of postmodernism, namely a "shift from a belief in facts to an awareness of perspectives...our attention is now focused on discourse and the role of language", as we construct our own beliefs and realities (Becvar & Becvar, 2006, p. 91).

Social constructionism.

The above constructions are expressed through a system of language (Becvar & Becvar, 2006). This acknowledgement moves us into the realm of the social constructionist paradigm, which can be understood as being underpinned by the constructivist epistemology. As a paradigm, social constructionism is "principally concerned with explicating the process by which people come to describe, explain, or otherwise account for the world (including themselves) in which they live" (Gergen, 1985, p. 266). From this perspective our descriptions are constructed through shared and agreed upon meanings and beliefs about the world and nature of reality. These meanings and beliefs are communicated though language and therefore "exist" in language. Language is thus not only a tool through which we describe our experiences; rather, it is a defining framework of them (Becvar & Becvar, 2006). Our realities, consciousness and ways of interacting with one another are socially constructed through our shared language, attitudes and ideas (Owen, 1992). Therefore it is the dominant social reality, rather than the observer alone, that shapes the creation of an individual's meanings and reality. Reality can therefore be seen as being constructed in a particular way, in particular social settings, and is influenced by our conversations with people, our contact with people and even by the spaces between ourselves and others.

Bateson (as cited in Held & Pols, 1985) defines epistemology as a set of assumptions held by an individual, which determine “habits of punctuating the stream of experience so that it takes on one or another sort of coherence and sense”; therefore, “the way one makes distinctions, the way one punctuates experience is one’s epistemology” (p. 510). Each individual therefore not only defines their reality through social constructions, but in a bigger sense defines their paradigm and epistemology by punctuating their reality and experiences in specific ways. In this way, individuals create self-narratives, which are properties of social accounts or discourse that undergo continuous change as a result of social interactions (Gergen, 1992).

McAdams (as cited in Ashmore & Jussim, 1997, p. 49) explains that “Each moment of social discourse brings with it new and particular expression of the self. Over time, expressions are collected and patched together, much like a montage or collage”. Due to the pervasiveness of social constructions, if individual narratives differ from dominant societal discourse, they are often subjugated or denied. Social constructionists, however, include the possibility of individuals deconstructing problematic realities or narratives, in order to reconstruct them and in the process create new meanings (Coale, 1994).

Social constructionist thinking is fundamentally postmodern in that the individual’s meanings and realities are viewed as constructed and not as absolute truths. The individual is viewed as the expert in his or her own life and hence social constructionist thinking focuses on “stories based on a person’s lived experience [rather than on] expert knowledge” (Doan, 1997, p. 130).

Narrative Theory

Brown and Augusta-Scott (2007) explain that narrative theory is rooted in social constructionism because its central premise is the idea that we live storied lives. They write, “we seek to make sense of our lives and experiences by ascribing meaning through stories, which themselves arise within social conventions and culturally available discourses” (Brown & Augusta-Scott, 2007, p. ix). Furthermore, stories are conveyed through socially prescribed language and social interaction within specific cultural contexts (Brown & Augusta-Scott, 2007). It is therefore impossible to separate the individual’s stories from the context, culture and community that form the backdrop to those stories.

Narrative theory is anchored in constructivist epistemology. It focuses on lived experience – because we cannot have absolute knowledge about our world, we need to explore how individuals organise their experience, make sense of it and attribute meaning to it. The meanings attributed to these experiences are based on each individual’s interpretation of those experiences. Bateson (as cited in Brown & Augusta-Scott, 2007, p. xii) states that “we cannot know objective reality, all knowing requires the act of interpretation”. Further to this, White (1991, p. 123) writes:

> It is the narrative or story that provides the frame for this interpretation, for the active meaning-making; that is through the narratives or story that persons have about their own lives and the lives of others that they make sense of their experiences.

White adds that these meanings inform our actions, and ultimately shape our lives. In Bruner’s words, “a life as led is inseparable from a life as told” (as cited in Genot, 1996, p. 53).

Polkinghorne (2004) explains that people give meaning to events in the form of stories that are constructed about these events. These stories are internalised and become a part of the individual's current identity and life story. Narrative psychotherapy attempts to revise these stories by deconstructing the client's stories and in the process facilitating the formation and creation of new, reconstructed stories. White (1991, p. 121) addresses the complexity of deconstruction as follows:

> Deconstruction has to do with procedures that subvert taken-for-granted realities and practices; those so-called 'truths' that are split from the context of their production, those disembodied ways of speaking that hide their biases and prejudices, and those familiar practices of self and of relationship that are subjugating of persons' lives.

It is possible then to deconstruct the realities and meanings that inform the daily lives of individuals by deconstructing individual stories or self-narratives, practices of self and relationship, as well as, dominant cultural knowledge and social discourse that underpin individuals' life stories (White, 1991).

Through the deconstruction of stories, narrative theory highlights the possibility of reconstructing new stories and new meanings in the context of dialogue. As a result, individuals re-author their narratives; they re-story their past, present and future life experiences; and ultimately shift their realities.

The above illustrates the fit between narrative theory and this research. In this research, one man's story is explored from his frame of reference, but is understood as being storied within the undeniably influential context of his family and society. Furthermore, the deconstruction of his story enables a reconstruction through the dialogue between me as the researcher and the participant, which in turn may furnish a re-edit of both the participant's and my personal narratives. Narrative theory is the platform for the qualitative research design adopted in this study.

Research Design

Qualitative Research

Longino (as cited in Becvar & Becvar, 2006, p. 338) states, “The social constructionist approach urges us to abandon the obsession with truth and representation... [it] rejects the idea that science is objective or that it gives us an unbiased view of the real world”. In this regard Becvar and Becvar state that “qualitative research has the feel of a perspective that emancipates people from the tight boxes of normative social sciences” (2006, p. 388). Furthermore, qualitative research recognises subjectivity and acknowledges that research of any kind is based on our representations of the world (Becvar & Becvar, 2006). The qualitative method therefore fits in the broader framework within which this research is anchored.

Denzin and Lincoln (2005) provide a generic definition of qualitative research by including the essence of all the various methods and approaches that fall within the category. Essentially qualitative research is “a situated activity that locates the observer in the world”, and it comprises certain practices and processes which allow for a different and new understanding of the world (p. 3). In addition, qualitative research studies phenomena in natural settings and endeavours to uncover the meanings people bring to them (Denzin & Lincoln, 2005).

Moon, Dillon, and Sprenkle (1990, p. 358) expand on this definition and add that "qualitative research aims to establish a meaningful dialogue between the researcher and the participant". It is through this relationship, which develops as the researcher immerses himself or herself into the world of the participant, that the complexities of the participant's experiences and world can be deconstructed. Qualitative research is thus characterised by the researcher taking a holistic, subjective and multidimensional stance, in an attempt to understand the meaning of complex events, behaviours and interactions in context, from the point of view of the participant. This methodology is consistent with the formerly mentioned constructivist epistemological framework which underpins this research.

A central premise in qualitative research is the emphasis placed on the social context in its endeavour to understand the social world (Neuman, 2003). A great deal of significance is placed on how the meaning of social or individual action is informed by the particular context in which it emerges. Neuman (2003, p. 146) argues that "when a researcher removes an event, social action, answer to a question, or conversation from the social context in which it appears, or ignores the context, social meaning and significance are distorted". This further implies that behaviours and events will have different meanings, depending on the culture, context and historical time frame. The aim of qualitative research is therefore to understand and describe human behaviour, against the backdrop of the time, place and culture in which it occurs (Babbie & Mouton, 1998). In essence this allows for a deeper and more meaningful exploration of the participants' worlds (Moon et al., 1990).

There are various distinguishing characteristics of the qualitative approach. The following were taken into account in this study: firstly, the research was viewed as a co-creation between me as the researcher and the participant; as such the rationale behind the research was clearly identified and shared with the participant beforehand. Secondly, the focus of the research was not to identify linear causes and explanations but to describe circular patterns and connections within the participant's story. Finally, the participant was selected based on individual difference and context, as punctuated by me as the researcher, rather than as a result of formalised sampling (Moon et al., 1990).

Research Method

Outline.

In line with the qualitative research method adopted in this study, this research aims to understand and describe one man's story of living with HIV/Aids in South Africa. It endeavours to provide a contextual description from which this story emerges and of which it is a part. This is done by considering certain contextual variables, including the dominant social discourse on HIV/Aids in this country and its effects on the participant's meaning systems and realities, and his biographical and cultural information. Further to this, the description includes a three-generational genogram. All of these are addressed in detail in the following chapter. Themes emanating from the story are described and deconstructed.

A single case study method.

As previously mentioned, this research adopts a single case study approach. Yin (as cited in David, 2007, p. 300) defines the case study method as "an empirical inquiry that investigates a contemporary phenomenon within its real-life context, when the boundaries between phenomenon and context are not clearly evident, and in which multiple sources of evidence are used". Although this accurately describes this method, a case study is most simply defined as such owing to the interest of the researcher in an individual case (Stake, as cited in Denzin & Lincoln, 2005).

Stake (as cited in Denzin & Lincoln, 2005) explains that in a case study, the researcher is continually engaged in the process in an attempt to understand its specific complexities. He highlights three types of case studies, and one of these, termed an *intrinsic case study,* forms the basis of enquiry of this research. The aim of an intrinsic case study is foremost to gain a deeper understanding of the case, or in this instance, the participant and his story. Because of an intrinsic interest the researcher endeavours to hear the stories of those "living the case" (Stake, as cited in Denzin & Lincoln, 2005, p. 445). Furthermore, it is this interest that draws the researcher towards understandings of what may be important about this particular case within its context. The research can therefore be understood as deriving its significance from the inside out, rather than imposing significance onto the case based on some or other theory or hypothesis. In this regard the research is an ongoing process of reflection, where the researcher is "committed to pondering the impressions, deliberating on recollections and records – but not necessarily following the conceptualisations of theorists, actors, or audiences" (Stake, as cited in Denzin & Lincoln, 2005, p. 449).

Case studies are descriptive in nature and provide rich, detailed imagery, which is the dominant reason why the method is being used increasingly in social science research (Terre Blanche, Durrheim, & Painter, 2007). Each case study has unique aims. In most instances the researcher aspires to observe behaviour and functioning, taking into account current and past contexts. The data gathering generally includes open-ended interviews, in the form of narratives, but other information is often utilised, such as historical background, personal and relational history, and alternate sources. The process facilitates qualitative understanding in the form of experiential knowledge (Stake, as cited in Denzin & Lincoln, 2005). Stake argues that this type of "naturalistic, ethnographic case materials, at least to some extent, parallel actual experience, feeding into the most fundamental process of awareness and understanding" (p. 454).

Furthermore, case studies have the power "to convey vividly the dimensions of a social phenomena or individual life" (Reinharz, as cited in Buki, Kogan, Keen, & Uman, 2005, p. 472). This research endeavours to describe, understand and deconstruct the social phenomena regarding HIV/Aids in South Africa, and the experiences of one HIV positive individual amidst it all. This research also stems from my intrinsic interest in the participant and in the subject matter and therefore the focal point is the uniqueness, context and story of the participant. In essence the case study method, as used in this research, is a reflection of human experience, which in turn is essentially qualitative as "case studies are largely the methods for disciplining personal and particularised experience" (Stake, as cited in Denzin & Lincoln, 2005, p. 460).

Procedure.

Two interviews were conducted with the participant. These were taped with a voice recorder and then transcribed. The transcriptions are available on request. The participant invited me into his home and explored with me his various work endeavours, to assist me in gaining a more comprehensive understanding of his life. This formed a fundamental aspect of this research as it allowed me a glimpse into the participant's world, enabling me to get firsthand experience of his personal and work contexts, and to engage the participant in his natural setting where he was most comfortable.

Case selection.

In a qualitative study “it is the relevance to the research topic rather than their representativeness” which will determine the sample selected (Neuman, 2003, p. 211). A primary concern when selecting a sample is how such a sample will “illuminate social life” and deepen our understanding of a particular context or phenomena (Neuman, 2003, p. 211). Moreover, cases are selected because they seem to offer an opportunity to learn, for the researcher and readers (Stake, as cited in Denzin & Lincoln, 2005). Because this research is a case study, the participant in this case was selected based on certain of the aforementioned criteria. However, it is important to note that the particular topic of this research emerged as a result of a process of the participant telling his story. Furthermore, it was due to the initial interactions between the participant and I that this research was established as a single case study. The selection of the participant is relative because the participant represents an extremely large group of the South African population, on the one hand, whilst his story is atypical and unique on the other.

Participant.

The participant is a man in his early forties who was diagnosed as HIV positive in 1986. In order to conceal his identity he is called David in this research document. More detailed personal and contextual information will be supplied as the story unfolds, and by means of the genogram. However, the narrative excludes identifying information and names were changed in order to protect the participant’s anonymity.

Data Analysis

Interpretive analysis.

The aim of hermeneutics, which is synonymous with interpretive data analysis, is to delve into an understanding and punctuate meanings of that which has not yet been understood. Through this process, an attempt is made to make sense of behaviours, processes and realities, which have been informed by context, societal discourse and language (Crabtree & Miller, 1992). Terre Blanche et al. (2007) use the aphorism, “to make the strange familiar and the familiar strange”, to describe the method of data analysis (p. 321). From a social constructionist perspective, this is done through subjective interpretation on the part of the researcher. Penn (1987) asserts that “as an observer, I am a part of the world I describe; that is I occupy two positions simultaneously – an inside and outside position, a meta-position and a participatory position” (p. 41).

Hermeneutic analysis can be understood as a process of deconstructing the participant’s narrative. Snyman (1998, p. 54) describes deconstruction as follows: “deconstruction is a process, a way of reading texts of the world, a way of constructing and deconstructing differences within texts.” I therefore used this process to gain insight into the participant’s text, by immersing myself in the participant’s story and by identifying themes from this story, as interpreted through my lens. In this way his story is deconstructed as I re-edited the meanings which he holds.

Trustworthiness

In the qualitative research paradigm, "reliability refers to the trustworthiness of the observations or data [and] validity refers to the trustworthiness of the interpretations or conclusions" (Stiles, 1993, p. 601). The following were therefore incorporated into this research study to ensure the trustworthiness of the observations: (1) Disclosure of the aim and expectations of the study, as well as any preconceptions, values and theoretical underpinnings which I hold; (2) an explanation of the participant's social and cultural context; (3) a description of the inner processes and impact the research had on me; (4) a focus on the development of trust between the participant and me, prioritising my willingness to understand the world from the participant's point of departure; (5) integration and grouping of themes which emerged; (6) acknowledging that I was a part of as well as apart from the process; and (7) focusing on *what* the participant explained regarding his experience.

Similarly, the following were adopted to ensure the trustworthiness of the interpretations or conclusions of the study: (1) Coherence, which is the quality of the fit and consistency of the interpretation; (2) fruitfulness of the study, in other words, making sense of the processes through which the participant was going; (3) self-evidence, which involves making sense of the experience of both the participant and myself as the researcher, and distinguishing between these two voices; (4) testimonial and catalytic validity, which refers to the validity of the information acquired from the participant and the extent to which the research process made sense to the participant; (5) and reflexive validity, which looks at the degree with which my values, thinking and meanings were challenged and changed by the research (Stiles, 1993).

Ethical Concerns

Terre Blanche et al. (2007) highlight three fundamental ethical principles, which they maintain should underpin all qualitative research. These principles are autonomy and respect for the dignity of the participant; non-maleficence, which requires the researcher to ensure that no harm comes to the participant as a result of the study; and beneficence, which holds that the researcher should endeavour to maximise the benefits of the study for the participant. These premises were adhered to in this research: the participant's anonymity was protected as identifiable details and names were changed, the participant's best interests were the priority at all times, and all meetings were scheduled to suit him. Finally, it was my primary aim and hope that the participant would benefit from the dialogue and co-evolution of a re-edit of his story.

As well as the aforementioned three principles, the following ethical fundamentals, as noted by Voster and Prozesky (2001), were also adhered to in this research. The participant's involvement in the study was entirely voluntary and he was made aware that he could withdraw from the study at any time with no consequences – this was stipulated in the signed consent form. The participant was also informed that he could withhold or remove any information supplied through the research process; however, this did not occur. The participant was informed that he could receive the transcripts at his request and a copy of the final research document was sent to him. Because the participant is regarded as the expert in his life, my aim was to learn from him and his story was therefore treated with the utmost respect. Lastly, I endeavoured to create a context which would result in a constructive and insightful experience for the participant.

With regard to the aforementioned ethical guidelines, both the participant and I signed a consent form, a blank copy of which is attached (see Appendix I).

Limitations

Each person who is living with HIV/Aids is unique and so too are their experiences and journey with the illness. This research focuses on one such individual. It therefore is a case-specific study and not fit for generalisation to other cases or populations. Furthermore, the focus is on the participant's subjective experiences and thus the findings and results reflect his perspective and lens.

Conclusion

In the following chapter the above methodology was applied to the case study by means of the following:

1. The preliminary interview is briefly described, which can be regarded as the first narrative of the evolving case study story. This interview reflects my initial ideas and reality regarding HIV/Aids.
2. Relevant themes are hermeneutically identified, which inform the nature of the subjective interviews. These themes constitute the second narrative of the story. Included are the participant's comments regarding the themes.
3. In the main body of the research the themes are deconstructed and discussed with the participant against the background of his experiences and life story – in the process creating a third narrative.

4. This ongoing process of reflection culminates in the final narrative, which is my own evolving understanding of HIV/Aids.

CHAPTER 4

PUNCTUATING MEANING IN A CONVERSATION

In any holocaust, war, plague or pandemic, there were always one or two people who lived to tell the story and why couldn't one of those people be me? Somebody had to stay alive to tell the story for all those who had died with their song still in them, unsung.

David Patient – HIV positive South African (Interview with David Patient, para. 10)

In this chapter the stories and themes that emerged from my discussions with David, the main character of this research, are woven together, and in the process a new narrative and new meanings emerge. As the storyteller, the chapter starts with my personal experience of meeting David, which forms the first narrative. David's story is the second narrative, whilst the themes which emerged from our dialogues make up the third narrative. As the narrator, the views and punctuations stated are informed by my interpretive framework, which also forms the theoretical underpinning of the text. The discussion is a deconstruction of the discussions David and I had. By giving a different meaning to both my own and David's experiences a reconstructed narrative emerges, providing another layer to his story.

The first narrative, or my experience of meeting David, was about meeting a man who had been living with HIV/Aids for a very long time. It became about deconstructing a label. According to White (1991), we give meaning to a narrative by focusing on the outstanding events in that story. Thus, David's story, the second narrative, is introduced by identifying the historically significant events in his life. Thereafter, his family is introduced by considering their genogram, the individuals who comprise this family, and their connections and familial patterns. Furthermore, the predominant themes which emerge as defining characteristics of his family are highlighted and discussed. Finally, the broader social context, which forms the backdrop of David’s life, is examined. The third narrative comprises the numerous themes that surface, as seen through my lens, in David’s story. Silence is the predominant thread, which weaves throughout, underlining and informing the various other themes.

Narrative 1: Deconstructing a Label

I was a bit apprehensive about meeting David. We met through a mutual acquaintance, our GP, whom I had told about my desire to do this research. It was he who introduced me to David, thus punctuating the beginning of our journey together. David and I had spoken on the phone and what I knew about him was that he was in his early forties and had been HIV positive for almost 23 years.

While driving to our first meeting, I wondered about the nervous ambivalence churning inside me. I felt anxious and uncertain about meeting David. Was this uncertainty emanating from all I had read and learned about HIV/Aids? Was it a manifestation of my own preconceptions and fears about the disease? Or was it just the nervousness one feels when meeting someone for the first time? It was a bit of everything I think.

Our journey began with a somewhat formal handshake. I met David at his shop; he has a passion for antiques. As I took my guided tour, I wondered about the man who collects all these artefacts; I wondered about the significance of the nursery round back, with its *hundreds of seedlings, perhaps a reminder of life, of possibility. David seemed enthusiastic to share his world with me, so he took me to his home nearby. What a wondrous learning experience it was – his home is filled with antiques, collectables, memories. His garden is alive with plant life and animals of all kinds, like cows and dogs. He runs a small guest house, through which he regularly shows aspects of his world to others. The space that he has carved for himself in this world is truly nothing like I had seen before.*

He made tea and we sat down for the interview. What proceeded was a gentle opening of two worlds, as our dialogue unfolded. This dialogue started with a somewhat predetermined script, which entailed various open-ended questions and themes that I had considered. As our conversation progressed, and we both felt more at ease, I found myself becoming mesmerised by his story. I became a part of the flow of the conversation by incorporating my own reflections and by using techniques such as minimal encouragers and summarising. What had begun as a meeting of two strangers culminated in a co-constructed dialogue between two individuals: David, in revealing aspects of his world and sharing his story with me, altered and coloured my own experiences. This meeting of the "other" challenged many of my taken-for-granted cultural and epistemological beliefs.

As I drove away, I was acutely aware of how different I felt. In grappling with why this was so, I realised that from my stance, David the label had evolved to become David the person, and the label was beginning to disappear. Furthermore, the dreaded disease HIV/Aids had become merely one thread in the colourful fabric of another's story. Reflecting on my own experience of meeting David allowed me to view his story with an altered and new lens.

Meeting David had fundamentally shifted all my previous experiences and notions of HIV/Aids.

Narrative 2: Introducing David

David was born in 1963, in the then Rhodesia, now known as Zimbabwe. He is the second of four brothers, with whom he shared healthy sibling rivalry and much naughtiness growing up. The family lived in a small farming community, and despite growing up during the war, he describes his childhood and family as “absolutely normal”. His father held a managerial position in a financial institution. He often had to travel on business which took him away from the family regularly. Prior to having children, his mother had also worked as an office manager. Once her children were born she opted to stay at home to raise her four sons. In reflecting on his life in Zimbabwe, David describes his family as “culturally a bit different” – his maternal family are Afrikaners from Angola and his paternal family are English, from central South Africa – the combination of which always made them feel somewhat different from the rest of their countrymen, as he remembers it.

At age 6, David’s family moved to a larger town in Zimbabwe. During his primary school years, sport was his passion. Although he remembers not being very technically proficient, he attended a technical high school, where he was a prefect. When he was 19 years old, the family emigrated to South Africa and settled on a farm in the Northern Cape. David attended university in Port Elizabeth, where he majored in marketing, although he never completed the degree as a result of having one first-year subject outstanding. He stayed in residence and shared a room with his best friend from school whose family had also emigrated. During his three years at university he regularly returned home to the family farm in the Northern Cape.

Thereafter, David spent two years in the army, before embarking on his career in the financial sector in Port Elizabeth.

In 1986 David was diagnosed HIV positive, after a routine blood donation. For four years he lived with his secret. The first person he confided in was his doctor. He then disclosed his status to his medical aid company and became their first HIV positive client – to date he is still with this company and describes his ongoing relationship with them as a huge support system. Apart from the medical personnel, only two other people know of his HIV status: his younger brother, who accidentally discovered his medication eight years ago, and now me.

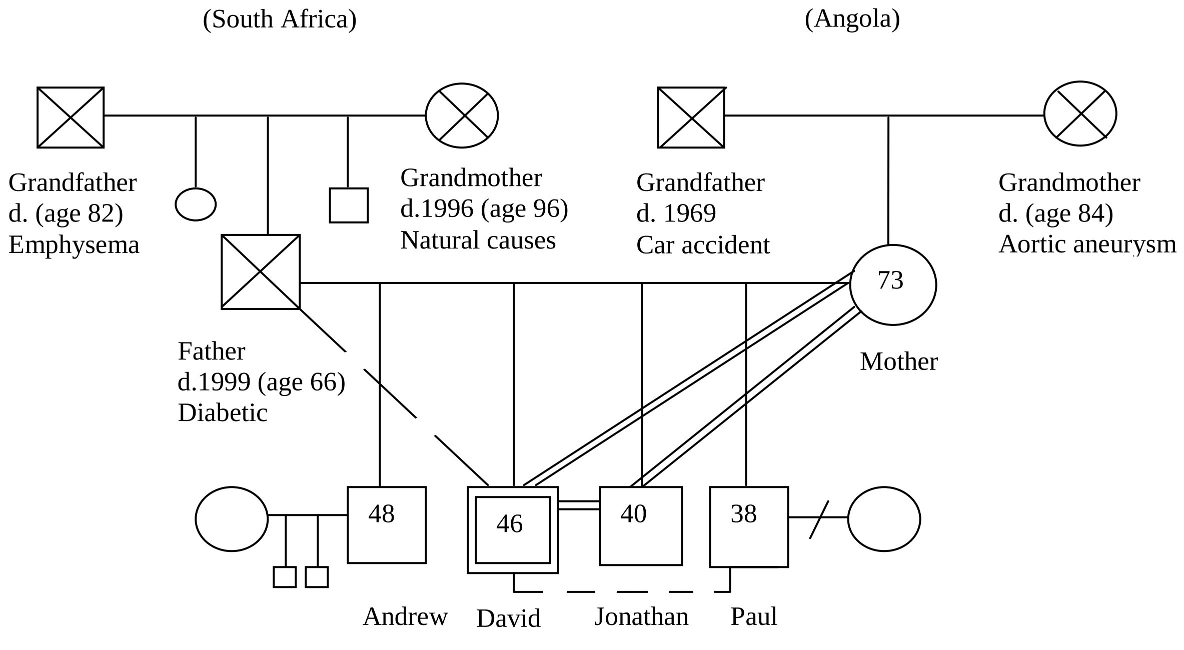
In 1988 David moved to the Western Cape to further his career as he needed a fresh start. Shortly thereafter his doctor immigrated. This was very traumatic for him as his doctor had been his only real confidant thus far on his journey with HIV. David attributes his drop in CD4 count and his high viral load at the time to the difficulty he experienced as a result of his doctor leaving. David was forced to find another doctor and to disclose his status once again.

About ten years after moving to the Western Cape David resigned from his highly stressful corporate position in order to leave the rushed life of Cape Town. He settled in a tranquil town nearby. Here he lives the life he had only dreamed of. He runs a few small businesses, which he loves. During the past 23 years David has never had full-blown Aids. He is a very healthy man with an undetectable viral load at present.

Introducing David's Family

From a systemic perspective, David can only be understood by looking at him within the context of his family, his community and the broader social context within which his story unfolds. The section below introduces his family of origin. David's family is first represented diagrammatically in the form of a genogram and thereafter is examined in more detail by briefly focusing on each individual member and on certain cross-generational patterns that emerged for me during our discussions. Secondly, the dominant themes which emerged for me in his family, through the telling of his story, are described. Finally, the broader social context which forms the background of their story will be illustrated.

Family genogram.



Legend:

Male	□
Female	○
Deceased	╳
Married couple	—
Divorced couple	–/–
Close relationship	⫽
Distant relationship	╱ ╱
d. Year of death	

Figure 4.1: David’s genogram

Individual members.

David’s nuclear family comprises his parents and three brothers. During our discussions his family members came alive for me. His mother is a pillar of strength, against which all the men lean; she is the heart of the family, and the boss. David’s father was quiet and played a more passive role in the family. His oldest brother appears to be very stable and hardworking, and he was David’s confidant growing up. His younger brother is his best friend, but became so only later in life; and lastly, David’s youngest brother, is seldom mentioned, perhaps owing to some distance that has always been between him and David.

During our discussions I asked David to highlight the various roles he believed each family member filled in their family growing up. He identified these as follows: His mother was “the boss”, she made the rules and handed out the punishment; his father was “the caretaker” – he looked after the family financially too; David explains that his oldest brother (Andrew) took on a “fatherly role”, acting as a substitute parent when their father was away; (Jonathan) was "the mischievous one"; (Paul) was "the baby"; and he saw himself as the one everyone thought was going to be "the successful one", because he always knew what he wanted.

Connections.

The above roles, as punctuated by David, provide a prelude to the interconnections within his family. Throughout David's story it is evident that there is a powerful bond between him and his mother – a bond that seems to have been there from when he was a very young age. His unwavering respect and love for her is still apparent in their relationship today. David also shares an extremely close bond with his younger brother, Jonathan, which is strengthened by the fact that he shares David's secret, and he is undoubtedly a fundamental pillar of support for him. They also share many aspects of their lives – they have mutual friends, various businesses together, and live close to one another. Jonathan is relatively close to their mother, although David remains her "blue eyed boy", as he teasingly confesses. This triad, consisting of David, Jonathan and their mother, is very strong – they spend a significant amount of time together, just the three of them, such as travelling overseas together.

David's relationships with his two other brothers are somewhat distant in comparison to the closeness he and Jonathan share. However, they remain in contact and appear to be on good terms. But this was not always the case. Growing up David recalls being closer to Andrew, owing to their proximity in age; similarly, Jonathan and Paul were very close. David's bond with his older brother was strong until he married, when their relationship shifted. With regard to his youngest brother, Paul, David offers few details about this relationship; he recalls that Paul "was just there". This reflects the distance between them. David and his father appeared to have been distant, a theme which seems to permeate all the father-son relationships in this family. This is probably due to his frequent absence from the home because of work commitments. As for his parent's relationship, David highlights their distinctly different characters and praises the endurance of their marriage. Although he recalls them occasionally arguing, the details of their relationship appear to remain private or respected, as he sheds little light on how they were with one another.

Multigenerational patterns.

There is an interesting pattern of female dominance on David's maternal side of the family. The women in this family are strong and powerful. He describes his mother as authoritarian, as a very hard woman, saying she is like a "bull". These characteristics she inherited from her own mother. Both these women ruled the roost in their respective homes. Conversely, the men in this family appear to adopt a more passive role; David remembers his father as being very compassionate and caring, and "very quiet". Likewise, his maternal grandfather was also the more yielding one. On his paternal side, however, the roles appear reversed – David's grandmother was, in his words, "very soft", whereas his grandfather was a "playboy" in his youth, although hardworking later in life, but nevertheless the focus around which that family centred.

There is another powerful illustration of the cross-generational patterns which emerge for me on David's maternal side, in that each of the past four generations uprooted and emigrated to a different country. Subsequently, each time the family had to re-establish itself in a new and unfamiliar place, having only one another to depend on. Interestingly, it was not out of choice that the families were uprooted, but rather in each case owing to political upheaval within the specific country. This seems to have brought about a pattern of acquired difference between and major shifts within nuclear families. In essence, each nuclear family diversified as a result of their specific experiences informed by the context in which they lived. The result is that David's families of origin, and his own nuclear family, are all quite different. David's maternal family were Afrikaners from Angola who made a living though farming; his paternal family were wealthy South Africans, who lost everything and had to make a new start in life; and his own nuclear family were Zimbabweans who were living in South Africa.

These multigenerational patterns allow insight into the ways in which this particular family relates and how their specific patterns of engaging evolved. By delving into the family's generational history and story it is possible to infer the dominant themes that form the rules of, and in essence define, this family.

Family Themes

Theme 1: Difference and otherness.

In David's telling of his personal story I hear a repeated echo about being different. This is mirrored in the story he tells of his family, who too were so often the other. They were a white family, from Afrikaans descendents, living in Zimbabwe. This made them fundamentally different from the main group – David remembers that "culturally we were a little bit different". He recalls, "We belonged to the Afrikaans church, and there were only three churches in the whole country." Even here amongst the sameness, familiarity was overshadowed by difference because they were an English family in the Dutch Reformed Church.

Leaving Zimbabwe was significant for the family, as a new struggle to fit in began. It was around this time that David began university and he remembers the culture shock: “I came out of...an English country, with English culture...and then I went straight into res. And I saw these students and I saw these people and I thought, ‘is this real?’” He continues, “I excluded myself...It was just a cultural thing of how they did things and I thought it was pathetic.” For him, moving to South Africa was a huge adjustment because as he recalls, “you just didn’t fit in.” Even after several years in the country, David was repeatedly reminded of how different he and his family were. One such example is when he joined the army. He says, “Obviously I had my regrets in the first six months of the military because it was an absolute cultural bloody shock.”

Being different has profoundly shaped who David is; perhaps this is what fuelled his yearning for independence. More importantly, however, being different strengthened the boundary around his family, and it became a defining characteristic that shaped who they were as a family.

Theme 2: Identity and belonging.

It would be impossible to divorce this theme from the one above as the very essence of the family’s identity was shaped by the way in which they differed from others. However, more specifically, for David and his family the struggle was about defining who they were on the one hand, and more profoundly where they belonged on the other. For David in particular, finding a place where he belonged was difficult from early on. For him, “High school was very different because it was a technical school... [and] I’m not very technically minded.” Belonging and identity were also something he strove for in all facets of his life, and this can be seen in his endeavour to be independent from his friends, “I wanted to be very independent,” he says. This characteristic was not only evident in David; the entire family was forced to be independent and self-reliant.

The family’s history is marked by a few significant events, which required huge shifts and change: change of country, change of identity – both inextricably linked to where they would find belonging. David’s family dealt with change by holding on to what was dear to them, one another; and by taking their memories with them, their prized possessions. They had to learn to treasure what they had, “you know we’re very sentimental, all of us.” David illustrates this further, “I got my first car when I was fourteen...I still have [it] today.” This thread is evident in other spheres of David’s life too – his house is filled with artefacts and numerous collections that represent his and his family’s life and journey.

Through this process the family was able to create a space that was theirs, where they belonged. They did this by constructing a new life, using pieces brought from their previous life to create their new puzzle. In this way they found a sense of belonging in South Africa.

Theme 3: The familial boundary.

One of the most striking themes that emerges from David’s story is the strong, seemingly impenetrable boundary around his nuclear family. One can hypothesise that the boundary around this family needed to be this strong because they were always different, and as such, in David’s words, “we were forced to stick together.” In this regard the boundary was informed by their context on the one hand, and by the attributes that punctuated their differentness on the other. The boundary is also evident in the family’s enormous sense of solidarity. David recalls, “we did everything together”, but moreover, they did what they did within their space. “Everything happened at home,” he explains. “My mother would always say ‘have as many friends as you want over to our house’.” Furthermore, wherever the family went, whether to church or to the occasional meal out, it was inevitable that “we went as a family. We always did”. The togetherness of the family can be seen as shaping and bringing forth some of the characteristics which made them so unique, and this in turn strengthened the familial boundary.

David’s family had certain family rituals that defined their identity and in turn created the boundary around them, such as eating supper together each night at the dinner table. He explains, “oh it was a ritual...every single night...everyone had their place at that table”, and “on birthdays the birthday boy would choose the menu.” Their family rituals served to keep them together, in David’s words, “our family was kept together...even today.” This boundary was somewhat impermeable, and was maintained owing to their seclusion from others. David describes his family as being “quite isolated”. Within their isolation they had one another; David affirms that “we could talk about anything and everything”. It is as though this was one of the family rules – we stick together and rely on each other – which can be seen as being born from the closeness they shared.

David’s family moved numerous times during his upbringing, first within Zimbabwe, and then later to South Africa. Each move had a tremendous impact on his family, to some extent it perhaps empowered their isolation, it simultaneously birthed opportunity for new connection, as well as having strengthened their interconnectedness as a family unit. David remembers how his family was able to rely on others, “everybody was there for everyone and helped each other...if you had no more fuel you borrowed from a friend.” The most fundamental support came from within the family; they stuck together and relied on each other. David highlights that this extended to the children helping their parents, “we had to help raise them [his brothers].” Their isolation in turn formed their connection to one another, and David believes that this profound connection is still evident today as they continue to rely on one another, “100%. Without being judged.” Another example is in David’s immense bond with his brother, who is like his best friend. Perhaps this is one of the profound spaces of true connection that David finds within his vast moments of isolation. In his words, “we have no secrets.”

Theme 4: The enduring effects of war.

David’s childhood and adolescent years were spent in Zimbabwe, a country which was for most of that time at war. Living during a time of war not only affected his family but also shaped the community within which David and his family lived; it created a particular way of life. For example, David and his siblings learned responsibility at a very young age. He says, “The trust my parents had in us, as kids at 15 and 17...” On the one hand this enabled David to learn to cope on his own, which today manifests in his uncanny ability to just get on with life, and on the other hand it united his family. “Weekend sleep-outs happened at my house. Mom was very strict about that. But also remember the situation, growing up in the war times.” In this regard, it is impossible to ignore the way in which the turmoil felt in the greater society influenced the strong boundary around their family. Moreover, it connected the community; he recollects that “It was a war time...We used to drive around with guns in convoys. It was that togetherness that was instilled within me”. Furthermore, the war instilled or solidified certain family values. “I wasn’t raised in a throwaway society...we didn’t waste, there was nothing to waste. So that was great, we shared. Everything was shared as a family unit amongst each other."

This illustrates how the context in which this family's story played out was so inextricably linked to the boundaries that formed around the family, as well as, the ways in which the family's identity and belonging were shaped.

Theme 5: Traditional family values.

There is a profound presence of a traditional value system that underpins David's family. Traditional values were upheld and enforced in this family. Numerous illustrations of this include the fact that they were taught to value what they had, to look after their belongings and treasure them. Furthermore, their home life was based on discipline and order; as David says, "we were brought up in a very disciplined home." This stemmed from the way things were done in the past, "you know mom had very staunch Afrikaner values – again I would say based on discipline and authority." There were rules – for one, David recalls, "we were never allowed to eat in front of the TV! The table was set." There was also a clear indication of hierarchy in the family. Although his parents were strict, they respected their children's differences and their individual decisions. David gives an example of the day he decided that he was no longer going to church with the family each week; he recalls his mother's response: "So she said 'you know what it's your choice, you've made a decision...' [And] she respected it."

Theme 6: Matriarchal family.

Stemming from the above theme is the unmistakable matriarchal nature of David’s family, which mimics his mother’s nuclear family and which can be seen in the multigenerational patterns. David reiterates, “I think my whole family values come from my parents. My mom mainly, I think she is a very dominant factor in the family, as was in her family. Her mother was also very dominant.” His mother was the authoritarian, she laid down the law and enforced it, she was also the shoulder to cry on and the one David and his siblings relied on. He confesses, “We were a bit fearful of my father...he was the head of the household.” He admits that his father “was always the figure head in the house but not the authoritarian, my mother was”. One description is that his father was more absent, both physically, because “he was out of the house a lot during the week days”, and emotionally too, “we could confide in my mother”.

Even today it is David’s mother who is the kernel around which the family is organised. Family gatherings are mostly arranged to accommodate her, at the farm, where she defiantly maintains the stable home base. David says, “we’ve said, ‘mom get off the farm and come and live with us...’ [But] she’s happy there. It’s home...She’ll never move.”

Theme 7: Stability.

The stabilising role David’s mother plays in the family can be seen to emanate from a much larger theme of stability that permeates their history. The family is able to maintain stability within the context of change, and this in turn is due to the solid foundations on which David’s family is built. This is not intended to imply that this family necessarily embraces change. As

David says, “we only moved...because of the economic or political scenario...Otherwise I still think we’d be in our same home.” However, what is evident for me is this family’s amazing capability to adjust and re-establish its grounding after experiencing change. As David says, to this day “we still live on the same farm that we bought when we left [Zimbabwe]”. Although his family story is one of being uprooted, David extracts the positive impact this has had on him. He explains, “I think that’s where I get my challenges from.” As a result he does not believe that “change has ever been hard for me”. Perhaps David’s abilities to deal with massive change throughout his own journey are evidence of the family’s acceptance of and resilience to change.

As is evident from much of the above, the context within which David’s and his family’s story plays out is imperative to understanding the way in which their lives and story were formed. In the following section this is considered more closely.

David’s Broader Context

David’s family story provides depth, as well as a different layer of meaning, to his personal story. It also allows for a much richer interpretation of it. However, there are many more layers to be included, and the context in which his story unfolds is one such layer. This context is his community and the South African society.

The diagram that follows illustrates David as existing within the context of his family, community and country. In addition, it marks three points of intersection along David’s path: The first marks his year of birth, and the second and third significant times in his life, all of which will be discussed in the paragraphs below.

Time Cable

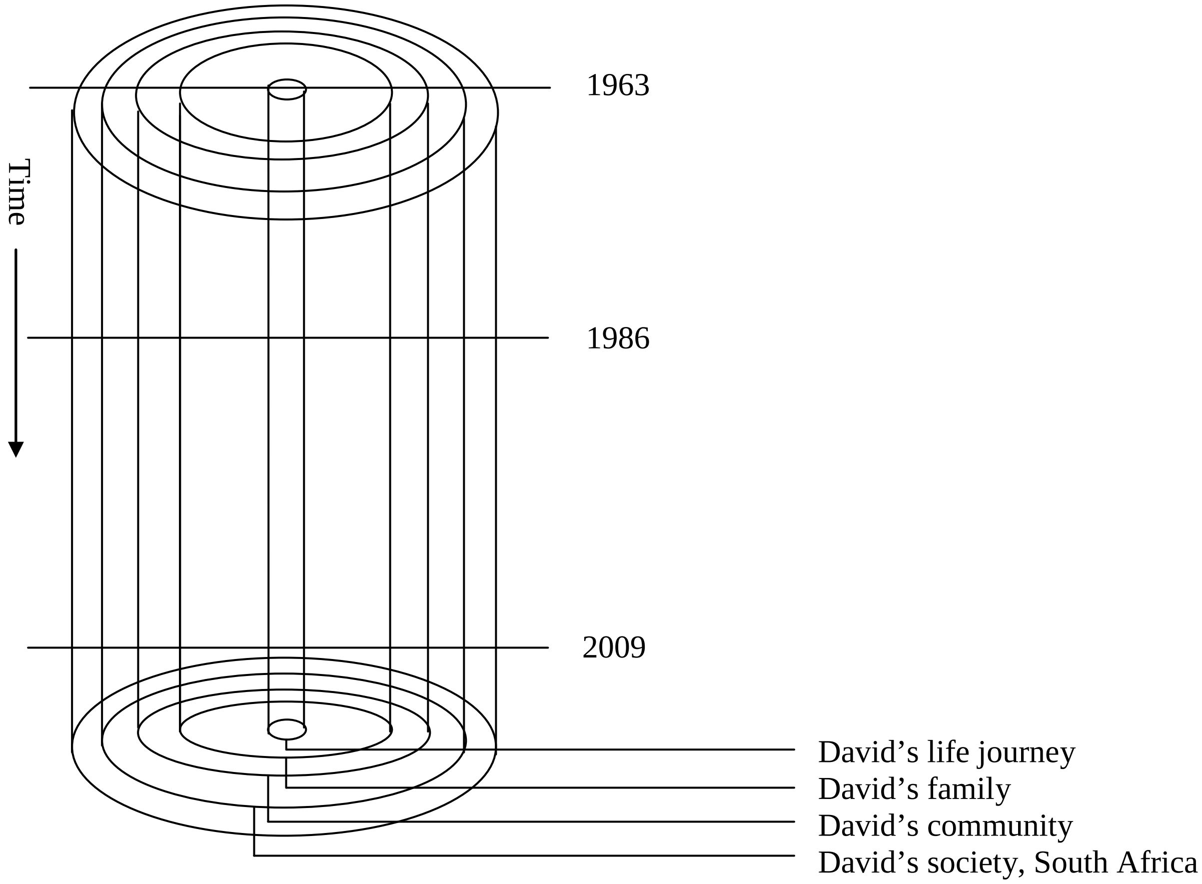


Figure 4.2: Time cable: David’s history

David’s Family

1963-2009.

1963: The family was comprised of mom, dad, Andrew and David; they lived together in Zimbabwe in a small farming community. Life for the boys was carefree and fun filled, as David describes it, and moreover, life centred on one another.

1986: The family had grown to include Jonathan and Paul; they had emigrated to South Africa by this time and were all adults, living separately, dispersed throughout the country; it was in this year that David learned he was HIV positive; it was at this time, as he recalls, that his “change in life came about”.

2009: David’s father passed away eight years prior; he, his mother and his brothers live their individual lives, but David speaks passionately of their connectedness – specifically the relationship between his mother, Jonathan and himself.

The story of David’s family, as articulated in the above descriptions of the individuals, their connections and their intergenerational patterns, is one of a family who stick together, no matter what life throws at them. It is a tale of connectedness and of belonging. This is certainly evident in David’s descriptions of his childhood; similarly, these patterns, which define his family, are echoed today in his close relationships with his mother and brother. What is perhaps contradictory to this is the fact that David chose to remain silent about his HIV status.

David’s portrayal of those first silent years, from 1986 when he found out he was HIV positive, until more recently when his brother found his medication and uncovered his secret, are indicative of a man on a solitary journey. He remembers, “Nobody else [knew]...I secretly also collected my medicines and I secretly drunk my medicines...” When juxtaposed against his memories of his upbringing, his journey with HIV must have resulted in a profound shift in his sense of his family and perhaps even in his sense of belonging within that family. Whereas before they shared everything with one another, this was and remains the exception.

David confirms this, “Because my mom doesn’t know and my dad passed away, he never knew, and my other brothers don’t know.” Moreover, many of David’s descriptions of his family centre on them always being somewhat different, but he had a place within that and as such his sense of belonging within the family was founded upon their shared differentness. In 1986 David learned about his status – he now was the exception to the familial rule of different-sameness. This is reflected in his ambivalence even today, regarding the disclosure of his status to the rest of the family, “I think it’s again fear of rejection – although I know it’ll never happen...and I’m thinking of my brother, if he had to know and I had to go stay with them again, would he think ‘well we’d better wash it like serious...’ but it’s not going to be like that, or I’m sure it won’t be like that.”

What is evident for me is the profound shift that must have occurred in David’s relatedness to his family when he began carrying the secret that differentiated him from them. Perhaps the reverberations redefined how he saw himself in the family? Perhaps his silence in turn shifted aspects of the relatedness within and between family members? Or perhaps it served to maintain the family rule of connectedness on the basis of different-sameness?

David’s Country and Community

David’s story is played out against the backdrop of South Africa. As such the South African people, their epistemologies and their belief systems are irrevocably entwined with his. Not only are these beliefs integrated into David’s personal narrative, through an internalisation of what he believes are externally held truths, but moreover, in a relational way they have shaped his every experience, and thus mark and define his personal truths, which have in turn shaped his life story. The impact of David’s context is undeniable and in order to understand its complexity, his beliefs around the evolving South African context will be described by juxtaposing his experiences today against his experiences in 1986, when he was diagnosed HIV positive.

1986.

During the 1980s HIV/Aids was a relatively new illness. However, as David recalls, “you heard about all the stories, you know Aids was like a dreaded word.” HIV/Aids already had a stigma, it had a reality and people held certain beliefs about it. David had little knowledge about HIV/Aids, and what he had heard was not good news – in his words: “I knew so very little about it, Freddy Mercury had...I mean he died.” He had heard the Aids stories, but he was in no way connected to them. This changed so suddenly on that day in 1986 when he became a part of the unknown, the feared, the stigmatised. He remembers the painful day that he found out he was HIV positive: “I’m still very angry and bitter about how I was advised...they phoned back and said, ‘oh you have a very special blood and we’d like to just do another test’...they had like all these questions they asked me and then they said ‘well are you aware’, and I said ‘no what are you telling me’ – and there was no counselling afterwards.”

His experience reflects the devastating effect the lack of knowledge about the disease at the time had, and it captures what so many others must have felt then – with no counselling, little support and a profound lack of empathy. What David remembers is harrowing, “according to them it’s like a few months and I’d be withering away and drying up like an old leaf that turned yellow.” Furthermore, there was no planning and no advice for the future, “even the idiots at the blood bank, I mean they just informed me, told me not to mess around, you know...it was weird.” It is perhaps as a result of these experiences that David decided “not to tell a soul!”

What is undeniable when listening to David speak of those lonely, fearful months is the power and influence of ignorance that came with a society that did not know. The question that emerges for me is to what extent this laid the foundation for his future decisions, and how it shaped all his relationships and interconnections with others.

1986-2009.

David speaks less about this time in his life – when he does it appears to be more gently and with some trepidation. Perhaps this is due to the remembrance of the complicatedness and solitariness of this time. What was going on around him was possibly even more terrifying. He remembers, “then the statistics were showing that there were more and more people being infected...” The escalating fear and not-knowing that reverberated around the country and world about HIV/Aids mirrored David’s inner world to a degree. David uses powerful language such as “people’s negative approach”, “outcast” and “rejection”, which captures how he must have felt during this time. He recalls, “mentally it was very challenging. Emotionally, I must tell you, very challenging!”

Through these difficult years David found the courage to get on with life, amidst the uncertainty around him. This is evident in his words to himself, for example, “I had to fight this on my own”; “I decided...that’s what I need, I need a change, I need to more on”; “the power of the mind is the most powerful tool and I think that’s what pulled me through”.

2009.

Some 23 years have passed: Are society's beliefs about HIV/Aids different? David is not so sure. On the one hand he acknowledges society's progression, saying, "you know what, there's medication, there's many people you can phone for support, and you know, that it would probably be easier to share the news with people that were close to you." He recognises that much has changed, "I would think people would be a little bit more informed", but he negates this in an instance, saying, "but you know it's a difficult question to answer because I am informed. There are still people that are now, at this point, at the same point I was then. They don't know what it's all about, so it's going to be as shocking to them as it was to me 12, 15 years ago."

David's words also unveil a prevailing negative reality and an example of the language used by many of his community members about the disease. He recalls a recent incident when he asked others what they would do if they were positive: "most people say 'I'd resign and go on a world cruise'. The other 50% say, 'oh god no I'd kill myself'." These words echo those same sentiments expressed by the staff working in the blood bank all those years ago – that HIV/Aids is likened to a death sentence. David believes that the gross naivety and stigmatisation associated with HIV/Aids is as a result of misinformation. He explains, "And for the most people, nobody worries or concerns themselves to read up about it; they hear it on the news; they know once you get it you die. Noting much has changed, believe me. There are a few people who are in the know."

The above illustrates the way in which the beliefs of those within his community affect his life each day. From the start of his journey with HIV the ideas, knowledge and meanings of others have formed an integral part of what it means for him to be positive. Moreover, they have shaped his personal narrative. It would seem that to this day David's internal and external worlds reflect vastly different truths, which quite likely rest on the attitudes and beliefs expressed by members of his community.

A Comment on Process: My Narrative

The two interviews with David were much more than conversations – they were a meeting of two people's realities that briefly became a co-constructed one. But moreover, they took place within the context of our personal truths and past experiences; aspects of his world, which I was invited into; and our broader context/s, our families and our country – and this is reflected in the process of our conversations. I entered the interview with my preconceived ideas; I was certainly there to listen to his "story of HIV". What I heard was so much more. By listening through the words, to the non-verbal, to the re-emerging interpersonal themes, and by taking cognisance of context, I realised the extent of the depth that encompasses one man's story. By allowing me to tread into his place of work and his home, David showed me much more than his words alone could reveal. It made me wonder about how his love of history could embody a search for continuity; how the guest house that he runs may serve to furnish ongoing connections to others, albeit at a distance; or how being surrounded by new life, in his nursery, provides a balance for living with a chronic illness. But by far my deepest learning was the degree to which the bravery of another's words could awaken aspects of my own silenced self. The shift in the process from a story of HIV/Aids towards an exploration of *two evolving persons illustrates the co-evolution that occurs in the meeting of two worlds. It is with this realisation that David's narrative is further explored.*

Extracts from David's Narrative

Before analysing the themes which emerge from David's story, below is a collation of different statements selected from the interview with David. These sentences are significant extracts that form part of his narrative. I have grouped them together to describe narratives of uncertainty and acceptance.

Narrative of Uncertainty

"I thought like 'oh my god how's this possible, why me?'"

"Look I mean you depressive, you depro. That's what you've got to deal with."

"Because you heard about all the stories, you know Aids was like the dreaded word."

"No access to any sort of information."

"Well of course it was a hell of a shock."

"Nobody knew anything about it back then."

"At the time I was like...how am I going to do this?"

"A lot of things I don't want to remember."

Narrative of Acceptance

"If anyone had to come up to me [now] and said 'I've been diagnosed with HIV 'I'd say 'right...go see that doctor, get onto that programme, or go to the clinic, and then get on with life. Tomorrow is another day. Pop your pill, get over it.'"

"it added so much value to my life. You know people just don't value their life, people don't value their health, people don't value the simple basics of life."

"I know the implications of HIV and medication and lifelong healthy living or whatever, it's normal, it's like living with any other manageable disease."

"to me it's just another manageable disease. I've got two that I'm managing, it's my high cholesterol, which I get chronic medication for, and my HIV, for which I get chronic medication."

"And what has happened has happened, you can't turn the clock back – but in a way I am blessed, in that I live my life. Because people don't live their lives, people don't live their lives, they exist. And they moan and they bitch and they don't appreciate little things, whereas I do. I think it's wonderful and I think that's why I am so...but you know I drive myself...Ilse you know I go to bed after twelve every night and I'm up at six every morning. And I know I need at least eight hours but I think six is fine. And I live my days! It's not that I'm trying to do so much before I die, because I'm going to live until I'm 90! But it's these challenges that keep you going – not to be successful for anybody, but for yourself. I don't know, it's weird, it's nice, it's wonderful."

"But I thought, 'here I've now been given a new lease to life, to live my life.'"

"And you move on, life goes on."

Narrative 3: Punctuating a Story

In the process of describing and giving meaning to a text or discourse, themes are identified and punctuated. Such themes are not from the text but are brought to the text in an attempt to describe some of the underlying dynamics of that story. The themes are not discovered but are distinctions that are drawn by the researcher (Bateson, 1951). In this discourse there is a central theme, which informs and gives meaning to the other themes. This main theme is silence and the supporting themes are uncertainty versus control; stigmatisation and discrimination; isolation versus connection; identity and belonging; the triumph of the human spirit; and, the untold Aids story.

Theme 1: Silence

While listening to, reflecting on and becoming immersed in David's story, a prevailing theme of silence emerged for me – a silence that began that day 23 years ago when David was first diagnosed HIV positive. This theme is not only a powerful undercurrent in my understanding of David's story; it also resonates with my personal grappling with silence.

To introduce this theme I have included the lyrics to Simon and Garfunkel's song, "Sounds of silence", from their album *Sounds of silence* (Simon, 1964).

Sounds of silence

Hello darkness, my old friend,
I've come to talk with you again,
Because a vision softly creeping,
Left its seeds while I was sleeping,
And the vision that was planted in my brain
Still remains
Within the sound of silence.

In restless dreams I walked alone
Narrow streets of cobblestone,
Neath the halo of a street lamp,
I turned my collar to the cold and damp
When my eyes were stabbed by the flash of
A neon light

That split the night
And touched the sound of silence.

And in the naked light I saw
Ten thousand people, maybe more.
People talking without speaking,
People hearing without listening,
People writing songs that voices never share
And no one dared
Disturb the sound of silence.

Fools said I, you do not know
Silence like a cancer grows.
Hear my words that I might teach you,
Take my arms that I might reach you.
But my words like silent raindrops fell,
And echoed
In the wells of silence

Between these words lies the essence of silence: Silence begins small, sometimes its significance is hardly noticeable, but often it slowly nurtures and its presence grows until it is always there, echoing sounds of silence. Silence exists within us, in the secrets we keep, in whatever remains unsaid; but more profoundly it exists in the spaces between us. Silence is in our speaking, in our hearing and listening. So it is found in both the unheard and the unspoken. It reaches our inner being – what we do not allow others to see – in so doing it shapes and alters our connectedness with others. But, as the writers say, silence will not be silenced; it will emerge in some way, to be heard only by those who know where it hides.

Another description, which I borrowed from field theory (Wheatley, 2006), allows me to conceptualise silence in a different way, as an invisible field that surrounds us. According to Wheatley (2006), field theory purports that our universe, which was once thought to be filled with nothing but empty space, is filled with invisible fields. These are fields that we cannot see; we can only observe their effects in our lives, and hence one only becomes aware of the powerful impact of these invisible fields through their visible effects (Wheatley, 2006). Silence in our lives is like a field because it is that which is not communicated between us, yet it fills the invisible space around us, and profoundly affects our relationships and our stories.

I believe that we cannot know the impact of the invisible field of silence surrounding each of us, until we are willing to trace its influence, which may run deeper than we care to recognise or admit. It is exactly this which I hope this section will do: to trace the permeating silence that I see emerging throughout David's story. In order to understand why his silence spoke to me so loudly I journeyed along a path of self-reflection. It was here that I began to grasp the silent spaces in my own life.

Layers of silence.

I first remember consciously thinking about silence on a cool winter's morning – 16 July 2008 to be exact, at about the time I first met David. As a part of our morning ritual, I was sitting with others in a circle at Agape Healing Community in Mamelodi. Lost in thought, I glanced up towards the kaleidoscope of graffiti on the wall in front of me. Gazing at the many images my attention focused on the intensely persuasive words written there: "Listen to the silence". The words reminded me of the lyrics of Simon and Garfunkel's song – which tell us *that these are precious prophesied words. For me this rang true; it felt as if these words were written with purpose, for me to hear. It was here that I began to grapple with the notion of silence in my life; I started listening to the silenced aspects of myself; and slowly I started finding the words to begin to share them with others.*

I am still tracing the path of silence and continuously discovering its impact in my life. For one, I have begun to identify the role of silence in my family of origin as it patterns through our history from one generation to the next. In my nuclear family I have uncovered a river of unspoken words that runs quietly beneath our outward connectedness. What I am grappling with is the extent to which this has impacted on my own style, because I have realised that there is much that remains mine alone, and that this silence exists in the spaces between myself and others. Moreover, I am continuously expanding my description of silence, for one I now understand it as a conserving theme in my life, as it functions to conserve aspects of myself that I deem unacceptable in the eyes of others. Mostly, I am wondering about the effects of silence on relationship. So, rather than try to understand why I choose certain pockets of silence, I am more interested in how these manifest in my various close relationships and in my connections with others. The process has allowed me to become more attuned, to really listen for the first time, to my own silence; and I hope this in some way enables me to hear past the wordiness, the obvious, to hear even the faint whisper of others.

The process was twofold as it happened both within myself and simultaneously as a result of listening to David's story. Perhaps it was here that I truly began my journey with silence. It is therefore imperative that I take cognisance of the inevitability of the impact of my personal journey on what I chose to punctuate in David's. Silence as a dominant theme in my life *colours the lens through which I look at David's life – in this way the retelling of his story is continually injected with my own experiences and personal explorations, and as such is a reflection of them.*

David's silence.

It is undeniable that the emergence of silence, as the theme which is carried throughout David's telling of his story, is a reflection of my own process on some level. It is because of this that I identified so strongly with this as a theme in his life. Furthermore, there are certain parallels that can be drawn which connect our individual experiences with the theme of silence: David also employs silence as a conserving tool, probably with far more efficiency as a result of a far greater necessity. The continuity of silence is evident in that it has been a constant companion on David's journey. Its strength as an influence in his life lies in the paradox that, whilst it is so profound and present, at the same time it is also completely ignored. The complex way in which this theme is woven throughout David's story will be described in the following paragraphs.

Some of the questions that arise for me are: To what extent is David's silence connected to the internalised label he carries of being HIV positive? How many of the meanings associated with this label has he internalised? To what extent is he identifying with the fear of what the potentially damaging and negative aspects of this label bring? And, to what extent has HIV as a cultural judgement had power over him, albeit in a real or imagined way? Therefore, before embarking on a deconstruction of the theme of silence, the notion of HIV as an internalised label will be addressed.

Silence and the label.

HIV/Aids exists on many levels: as a disease, but also as a label in a culture that has attributed many meanings to it. Regardless of the fact that no one really knows that David is HIV positive, this “silent” label is a load that David carries with him. The load of this label would, if it were known, undeniably colour the lens through which he is defined and understood by others.

One description of David’s apprehension about disclosing his status, and his decision not to, is that it stems from his internalisation of the label HIV/Aids. He says, “I’m still afraid to talk openly about it, I’m sharing it with you because Dr Jones introduced us, but I mean no, I wouldn’t talk to anybody!” His silence is entrenched and his non-disclosure unequivocal, based on the real and imagined consequences inherent in this label. David expresses his uncertainty about these imagined outcomes through an example of his family: “Do you ‘soen groet’, you know kiss hello, or do you now pass the cheek, because people are funny when it comes to things like that...it’s what I’m conscious of, and maybe wash your hands after you shake his hand.” These meanings attached to the label are undeniably contributing to his continuous choice to remain silent. He attests to this and explains that after all these years, “I’m still living in a box.”

To state that HIV/Aids is what colours our perceptions is an oversimplification which would too comfortably shield us from a more difficult reality – that our struggle in meeting the labelled other is not so much about them, but is in facing our own epistemological truths. Meeting someone with a label, such as HIV/Aids, confronts our experience of that label on the one hand, and our underlying epistemological lens, on the other.

Perhaps my own uncertainties about meeting David emanated from my personal truths about the disease, informed by a prevailing cultural judgement and from my internal epistemology – that HIV/Aids is equated with hopelessness and inevitable death. I realised that I had felt sympathy and sorrow for David, before we had exchanged even a single glance. Moreover, I had implicitly drawn the lines of distinction between myself and David on this one difference between us; I punctuated the disease as the pivotal point of distinction. He is HIV positive, I am not. Reflecting on my own uncertainty about meeting David forced me to think about the extent to which my personal epistemological stance, born from my cultural context, is embedded in, and informed by, this uncertainty. Similarly, each of our perceptions of the other, and more specifically of the label, is created in this way.

The prevailing silence.

David had been a regular blood donor, up until that day in 1986. After donating blood, he received a call from the blood bank telling him he had “very special blood”. He was called in for further tests and was informed that he was HIV positive. David remembers, “I had nobody to talk to” and he told “not a soul”. For four years David lived in absolute silence regarding his status, and he remembers that “emotionally, in the beginning, it was terrible”. When it became too difficult he made a decision to disclose to a doctor. He remembers, “I needed to tell somebody because I just really needed to talk about this disease and get some feedback.” David describes how significant this minimal support was to him. Then his doctor decided to emigrate. This was a big blow for David and it was frightening for him because he would once more be faced with the decision of either living in total silence or having to disclose again. He recalls, “I hit a bit of a dip because now I had to disclose myself to another person.”

To attempt to understand how David’s silence is maintained, it is necessary to expand the influence of this silence to the larger social context. Through my lens his silence is to an extent birthed from the community within which his story unfolds. The dominant societal beliefs fuel David’s reasons for non-disclosure. As a member of the South African society, his personal reality is steeped in and informed by considerable ignorance, misinformation and stigmatisation around HIV/Aids, which he believes is evident in current societal beliefs about the disease. David explains, “People’s negative approaches, even my family, it’s like ‘don’t let children go near him...don’t kiss him’ ...people just didn’t know. Still people don’t know. I mean already you feel as if you are now an outcast and I didn’t want to be rejected by friends and family and colleagues...I mean people still discriminate, extensively, or terribly, without a doubt.”

Such societal beliefs are what, over time, entrenched the fear of disclosure for David. Twenty three years later, still only a handful of people know that he is HIV positive, and he lives in silence about his disease for the most part. He admits that he is not able to break the silence because of the judgement and discrimination regarding HIV/Aids, and adds, “The rejection, bear in mind there would be huge rejection! And like, can I touch you. You know people are still so stupid.” His internalised understandings of society’s ignorance, as well as his belief in people’s fear of the unknown, which is rooted in his understanding of the dominant discourse of the world around him, is what seems to have caged him in silence. He empathically notes and confesses that “people are just afraid, I mean I’m still afraid, to talk openly about it”. Yet there is a paradox in this: Whilst his HIV status marginalises him and the wall of silence traps him, it seems to him that it is his non-disclosure that simultaneously serves to keep the connections of relatedness in his life intact – a bind which makes the risk of breaking the silence that much more frightening.

Pockets of non-silence.

The predominant silence is contrasted by the comfort and support he continues to find in the spaces of non-silence, which have inadvertently emerged in the enormously supportive relationships with his doctor and medical aid company, and more recently with his brother. This support network has been vital in carrying him through the silent pathways of his journey. It is evident that this marks the difference between the ignorance that comes with the lack of knowledge, and the support and understanding that comes from being informed and educated. For David there are very special moments that emerge when he is given the space to talk, without being judged or discriminated against. He explains, “there is a need, I mean I like to talk about it, not to anybody and everybody, [but] it makes me feel good – it’s a happy story! I think so.”

Society, through its constructed discourses around the disease, maintains his silence because of the “huge stigma and discrimination” that surrounds HIV/Aids. Paradoxically, as he further points out, “Aids doesn’t discriminate. Aids doesn’t choose a sector of society.” However, after such a long time the silence about his status may be so entrenched and woven into his personal story that the risk of breaking it and then having to re-edit his entire story may be too great. One can ask: Is the fear that it might result in an invalidation of his 23 years of his life? Choosing to remain silent has directed his life path in a particular way, and has resulted in a particular life story. This is his story and his truth. Silence is part of that story. To change this now would require such a profound shift, it would entail taking a new direction on the path of his life and it would involve an entire re-edit of his HIV story to date, and in the process would bring into question layers of meaning. Where silence was a choice initially it has now become a reality and a truth. Despite knowing and understanding this, he confesses, “I often wish somehow it’ll just slip out.”

Silence as protection.

One way of understanding silence in David’s life is in its capacity to protect both him and his family. On the one hand, from David’s perspective, his silence really does serve to protect his family. He explains this through his expectation of the pain his secret would cause his family. He describes the foreseeable “emotional trauma they would go through” were they to find out. On the contrary, however, when his brother did uncover his secret the reaction was unexpected. David recalls, “But no, no, he accepted it fully and became my pillar of support in fact. It was almost like a relief that he knew because at least somebody else knew.” On the other hand, possibly more comforting, is the protective, safe shield the silence forms around him. David verbalises the extent to which his apprehension to disclose is based on this, “No, there would’ve been too much sympathy...they would’ve just been overly supportive.” Moreover, without the shield, he would suddenly have been different, “they would’ve felt sympathetic towards me, and they would’ve handled me more gingerly.” But that is not how David wants it. He continues, “No, what for? We’re normal...You know maybe it would’ve meant if I’d asked mommy for something I’d get it, you know, like a spoilt brat, because shame you know he’s dying. Oh no!”

Despite the comfort and protection the silence brings, David grasps its inevitable demise, and foresees its end. He confesses that he would tell his family, but “Only if I got sick. It’s only fair”. This undoing of the silence which has so long protected his family might provide a new shield for David. Right now he finds comfort in the fact that if he got ill, “at least there is somebody to look after me [his brother], if I’m like in bed and can’t move – you know you see in the movies – that there is someone in the family that can support me”. Perhaps in time David could find protection in his non-silence too.

The re-edit of his story.

David has walked a long path with HIV; a path that he was thrust onto, blindfolded and alone while being ripped from a soft reality. He has spent each day since creating a new life, a new story and a new David. Breaking the silence would mean once again being thrust onto a different path. Would he want to do it all over again? Disclosing his status now would entail more than a re-edit – an entirely new script would be needed. He says not: “No, I don’t think...you know because I have come so far...and life as it is now is as far as I am concerned is for me normal. Life for them...you know is normal. So if I were to go and expose my status now, it’s like, why do you want to throw a stone in the bath?” In David’s eyes, the stone would change everything, even his relationships with his family. He says, “there would be too much sympathy.” He explains further, “I just know that with my immediate family they would’ve been too sympathetic towards me and concerned, the constant ‘how are you feeling’, no, it’s just fine the way that it is.” David has worked hard to create the life he has and to maintain his relationships with others; breaking the silence now would require an entire redefinition of himself in relation to others, and hence of his entire narrative.

Theme 2: Uncertainty versus Control

“My change in life came about when I was diagnosed as HIV positive.” From a life that had been fairly predictable, that moment changed everything. It had a profound effect that permeated every aspect of David’s life. It marked the beginning of an altered script and many changes that subsequently followed. The uncertainty that it brought about dissolved every ounce of control he had. Although one could argue that this life-changing moment was not one of choice, every conscious decision he has made thereafter has been. In the following paragraphs the path of choices he made will be traced, resulting in the new script and current reality they eventually created – and ultimately culminating in a shift from uncertainty to control.

Being HIV positive changed David’s known and predictable world and many personal truths he had held were suspended. Suddenly everything had new meaning, everything was perceived as a possible threat, as he tried to make sense of the unknown he was facing and the uncertainty he had to deal with. He remembers, “I mean everything that came out I’d think ‘God it’s a lesion’...and I was blooming paranoid...Everything I got was like ‘ah, is this Aids related’?” This uncertainty created a vacuum, which he tried to fill with an increasing need to gain mastery and control in his life.

Sitting alone on his balcony, the night he found out that he was positive, David started making what would be the first of many decisions regarding the way in which he was going to live his new life script. He remembers, “It’s the closest I ever came to suicide because God, I can’t live like this...[then] I said ‘bugger it, I ought to know a little bit more’; I then began making decisions.” This moment not only punctuates facing uncertainty and taking control as a recurring theme in David’s journey, but also marks the beginning of choices which confront the changes as a means of taking control, amidst the unpredictability and uncertainty that were now an inevitable part of his reality.

The first and most important decision David made was to remain silent. By not speaking to anyone, by keeping his status a secret, he overtly controlled the effect it had on how he was seen and on his interpersonal relationships. By remaining silent he kept a modicum of control in relation to his external world. Because of the uncertainty at the time he perhaps felt that his life could have spun out of control if he had revealed his HIV status.

Silence did not have this effect internally. On the contrary, it probably fuelled the uncertainty because he could not do any reality testing. So, bringing about change as a way of dealing with this uncertainty was as a way of coping for David. His decision to move to Cape Town is the first example. On the one hand, amidst the uncertainty, he just wanted to run away from it all, far away from the frightening reality of being positive, and from the blood bank which he could see from his apartment. Looking at it was akin to facing this horrible truth and being reminded of it daily. David explains, “the crazy part is you know my apartment overlooked a portion of the blood bank...and I said ‘I can’t face looking at it’...you know it was just too much...but at the same time I needed to know more...so I decided that’s what I need, I need a change.” Perhaps Cape Town also represented autonomy – a place where he could easily disappear and hide, even from himself. However, the move was the first step towards a new beginning and a new future for him. For David it marked the beginning of embracing this new reality and facing the future. It set in motion what was to follow.

Deciding to learn about his illness was the next step in taking control in his uncertain life. It began with his search for information about this disease, which for him was an exploration for meaning and for understanding, and it marked his initial grasp for control. It was a solitary struggle in a country where little was known about HIV/Aids at the time. David recalls the limited literature he found, “it was called an encyclopaedia. I think it had 85 pages...an encyclopaedia of Aids and it’s 85 pages!” Regardless, this was an important first step for him. The second step was, as he recalls, that “I started looking after myself”. A fundamental shift occurred when David decided to live a healthier life and in so doing began really taking care of himself. It put him on a path towards overcoming the potential threat of HIV/Aids and gaining power over the disease. To this day his health is of paramount importance, “I take multi-vitamins, I eat right.” It was another small step, but its effects were profound in that it enabled him to feel more in control of his life.

A third essential step was when David decided to disclose his status to another, his doctor. This decision enabled him to share the burden and to gain some much needed support. He remembers, “I just really needed to talk about this disease and get some feedback.” Moreover, it culminated in further gains as this one relationship supplied him with more information, better medication and helped establish the vital relationship with his medical aid company – one which to this day represents a powerful pillar in the maintenance of control over his disease.

Slowly the balance of uncertainty versus control has shifted towards gaining control. The turning point came when David began planning for his future, a future about which he had been ambivalent until then. More specifically, he dealt with uncertainty about his future by anchoring his life in a series of goals – “five-year plans, and I had to achieve what I had planned because I wasn’t going to live to 35, I wasn’t going to make 40, and I’m nearing 45”. As a result life, for David, has become a challenge “a very exciting challenge because the best part of it is that I’ve set these goals and I’m achieving them”. Recently, David took a final step in taking control of the disease and of his life, when he decided to resign his stressful job in corporate Cape Town. He chose to begin a kinder life for himself, one where he is the number one priority and where he has achieved the success he hoped for. He triumphantly says, “So I passed the five-year plan thing now, now I’m just living.”

Initially actively taking control was crucial. However, it would seem that David has no need to take that kind of control anymore. It helped him through when he feared the end; it enabled him to take the necessary steps to face the future, but it is no longer required because he has surpassed being a victim and has become the navigator in his life. In listening to David’s story I wondered how anyone overcomes such challenges. Now I understand that all of the aforementioned steps emanated from and were enabled by David’s belief in “the power of the mind [it’s] the most powerful tool”.

In the sense that uncertainty and control are an inevitable part of any life, this theme continues in David’s life. However, the way in which David embraces uncertainty has been fundamentally altered as he dealt with a difficult situation emanating from his silence. The example is how he handled his brother finding out about his status. At once the comfort and safety that his silence regarding his status had provided was inadvertently shattered – his brother had found a stash of his medicines. David took it in his stride and embraced it, allowing this dreaded inevitability to become a part of his story. He remembers, “it was very emotional, [but] wonderful! Wonderful and supportive.”

Although David has conquered the uncertainty, the threat of the uncertainty returning lurks in the distance, because at some stage in the future he may get sick. However, it appears to me that David has accepted the inevitability of uncertainty as a part of life. He jokes that “like I said to Jonathan, ‘what I’d probably do, if I knew I was on my last legs, I’d probably get into my little Spider, my Alfa, and I’d drive off Chapman’s Peak’...But I wouldn’t do that because I’m not that way inclined, I mean if I was going to do it I would’ve jumped over that ledge the day I was told I was positive”. David has conquered the uncertainty. Defiantly he proclaims, “It’s not going to happen! I’m not going to get sick. So I don’t even think about it.”

Theme 3: Stigmatisation and Discrimination

Meeting David exposed my preconceptions about HIV/Aids and it brought to the fore my own unspoken, unconscious beliefs about the disease and the people infected by it. I attribute the ambivalence I felt within when meeting him as confusion that manifested on two levels: Firstly, it was about my knowledge of the “known” facts about the disease versus the trepidation associated with not knowing what to expect from David, which in turn emanated from the stigma attached to the illness. Secondly, I was unsure about my role as researcher meeting the “labelled” participant on the one hand versus me meeting another person, on the other.

The following paragraphs address this very issue by attempting to understand how David has experienced this stigma, whether real or imagined, and how this has imprinted on and moulded his perceptions, his reality and life story.

Notions of stigmatisation and discrimination emerge as a powerful and influential force in David's script, one which has guided and informed so many of his choices. For David there is no distinction between real and imagined stigma, only his perceptions about what others think. For him, stigmas associated with HIV/Aids are massive, inescapable and real. Furthermore, he undoubtedly feels the discriminatory effects of these stigmas. He explains, "you feel as if you are now an outcast and I didn't want to be rejected by friends and family and colleagues at work...I mean people still discriminate, extensively, or terribly, without a doubt. And it's so sad."

David's words clearly illustrate the ever-present effect of stigma in his life, but even more profoundly they demarcate him as different from others, as an "outcast". The stigma makes him different, and as a result who he is has been altered, which in turn has changed his conception of himself. David explains, "there is this taboo, it's that if you have this disease, you're going to die; and it's about the shame." This emphasises the hold the stigma has over David's experiences. It also illustrates how the externally defined taboos, which emerge from the stigma, have been internalised and are experienced as shame. Stigma has become a self-defining attribute, one which is integrated into David's identity, and which has altered it permanently.

Throughout David’s story, his closeness with others is continually juxtaposed against the silent distance that exists between himself and others. This can, on the one hand, be understood as emerging from the secret he carries, but on the other it is maintained by the stigmatisation that David experiences with regard to HIV/Aids. He believes that “some people are still of the opinion that Aids is going to change the world, the population explosion, Aids is going to solve this country’s problems. You know whenever you’re in a discussion and the subject comes up and they’re like, ‘thank God for Aids’, and I’m just thinking ja right!”

In each such moment the distinction between David’s outer world experiences, in the silent spaces between himself and others and his inner world, his unspoken thoughts and feelings, is accentuated. This also illustrates how stigmatisation creates distance between David and others, and how it perpetuates his perception of being different, of being the other. Needless to say, the distinctions which punctuate these differences are informed by the dissonance between David’s personal understanding of HIV/Aids, and the lack of insight which is reflected in the stigmas held by others. He points out, “people talk about... ‘god this Aids is just not happening quick enough’. Aids doesn’t discriminate. Aids doesn’t choose a sector of society, and you think of all those Aids orphans, what a cruel thing to say!” This illustrates how overtly expressed stigmatisations define relationships for David between himself and other individuals who are a part of his life. Furthermore, it provides insight into how distance is maintained in his life through experiences that repeatedly mark him as different. Finally, David’s internalisation of being different made his journey an alone one. In this regard he reveals, “it’s been a long, solitary journey.”

If living against a background of stigmatisation and discrimination has made David’s journey a solitary one, one can conclude that he was left with little choice but to master the art of remaining silent. Although he says, “I don’t mind speaking about it, but people’s negative approach towards anyone [who is positive], even my family, it’s like ‘don’t let children go near him...don’t kiss him now’.” Because David remains untrusting of what others’ perceptions of him would be, owing to the negative attitudes he perceives them as having, he still chooses to remain silent about his status. “There’s huge stigma and discrimination...I would consider telling people, but...you know they always look at the negative side of things.”

David’s uncertainty about disclosure can also be described as emanating from the belief that he may not be accepted if he were to disclose, that he too would become a member of the stigmatised, labelled, HIV positive other. He articulates his fear as just this – the fear that he would be rejected. He says, “And the rejection...you know people are still so stupid, or if you sneeze it’s like ‘stay away!’” He reiterates this, “I think it’s again fear of rejection, although I know it’ll never happen, but it’s just, people are still so uneducated about HIV/Aids.”

The unspoken message, borne from the stigmas and the adjoining discrimination, is one of deep-seated hurt and frustration about the inability of others to see past their stigmatised lens. In his words, “they don’t know what their attitudes are doing.” He confesses, “You see I appear very strong, but there has been a lot of hurt that has come along with it. A lot of hurt.” It continues to be a part of David’s experiences; his journey is marked by unavoidable moments where stigmas emerge and are reinforced through conversations with others. The uncompromising rigidity of other beliefs, expressed in the stigmatisation of HIV/Aids, is mirrored by David’s abiding perceptions. He categorically says, “I still believe there is such a huge stigma attached to it – if you have the disease it’s a death sentence. They may have heard that you can get medication and can live on it, but you know what – you going to die mate! Bottom line.” Finally, the stigma has silenced David.

Theme 4: Isolation versus Connection

The pendulum swinging between isolation and connection has been a continuing feature in David’s life. When his HIV story began it swung to the side of isolation, and he was alone. His status brought isolation. He remembers, “I had nobody to talk to.” David made attempts to connect with others who shared the same burden of this secret; but even here David did not find solace. He tells it as follows: “...two years ago, I went onto the internet and I interacted with people with HIV/Aids, just because I needed to speak to somebody else who was positive...And I met these people and...I could only share my experiences and they could share theirs, but I thought I feel so sorry for you. They’re all sick, because they’re making themselves sick! They think they’re sick, so now they are sick.”

Even in the company of other people who are HIV positive David is alone. He is different because of the way he has chosen to define his reality, and he consequently struggles to find connection. He says, “But you see...I don’t know how other people are, and I did go out and talk to other people. But most of those people were depressed, their lives were ruined, they were waiting to die.” Once again he realised, “I had to fight this on my own”, which reinforced his isolation and once more placed him within the silent pathways of his journey.

The pendulum has now swung towards connection. Paradoxically it is his silence that has facilitated him to once again have ordinary and meaningful connections. His life is populated with friends, family and colleagues. Ironically, it is the fear of losing these connections which on some level maintains the silence in his life.

Theme 5: The Triumph of the Human Spirit

David’s story is one of tremendous courage. There is a continuous thread of strength and hope that weaves itself throughout his story, holding it all together. This thread is the triumph of the human spirit, of David’s triumphant spirit. His ongoing belief in himself and in his ability to surpass the “death sentence” handed down to him in 1986, are testimony to his positive attitude and unwavering determination to choose life. In the following paragraphs examples of his inherent ability to persevere are given.

It began the day David found out he was positive, when he was sitting alone on his balcony that night contemplating life. It began the night he chose life: “I think people with weaker personalities or emotions, I think they’d have jumped...it depends a lot about the person themselves.” David is not one of those people; he believes in people’s ability to take control and manage their lives. He explains, “I also have this belief that the power of the mind is the most powerful tool and I think that’s what’s pulled me through.” This is evident from the beginning of David’s journey with HIV. Moreover, this belief has underpinned the changes David has made throughout the course of his illness – the decision to manage his illness for one, and to take control of the way in which he was going to live this life. He explains, “I also think it’s a mindset, you know I think people make themselves sick. You know if you are in a job that you really despise, you are going to make yourself sick so that you can stay at home;

or you’re not going to give two hoots if you fall ill because what have you got to lose, now you don’t have to go to that work-hole. Whereas I love what I do!” For David, however, it is more than this; his happiness in his job and life are determined only by the choices he was able to make because of his mindset. David’s story is a testimony to the power of the mind; he believes that, “if people looked at the disease in a positive light, bear in mind that you need the tools to manage it, you have got to manage it and take control...and within yourself you’ve got to say, ‘I’m going to beat it!’ I have!”

Throughout his complex journey David has created meaning in his life. It is as though his illness has created a new awareness of what really matters in life. He poetically points to what he believes most people somehow overlook and never fully understand: “Let me tell you, when you wake up and you think: ‘Do you know how lucky I am just to be able to wake up, do you know how lucky I am just to be able to walk out and appreciate this wonderful day.’ You know, people look past life...people just forget about how lucky one is, how privileged you are to just get up and enjoy the day, watch the sunset, walk in the rain...But you know when you really only get to realise what you’ve got, when your lifetime has been shortened.”

David’s story is testament to the possibilities that are created through the choices we make about how to deal with what happens to us, and ultimately how to live our lives. He triumphantly states that, “We can all take medicines, we can all take the pills, but it’s your outlook, I think the mental side of gearing yourself up and fighting the fight. It’s the power of the mind... I mean some people can bend spoons, well I can extend life. And that’s what I’m doing.” This highlights the ingrained belief David has in his capability to manage his destiny.

It is what allows him to continue and it undeniably strengthens the firm grip he has on the disease. He explains, “That’s why I’m not sick; I’m telling you now...you think yourself better. I can’t tell you the last time I was ill. As in flu, or a cold, or lying in bed.”

It is difficult to fathom that this man who embodies such overwhelming positivity is also living with an incurable life-threatening disease, and the extent to which his triumphant spirit infectiously permeates every facet of his life. About his journey David says, “But how fortunate it’s been to actually live your life as you want to live it, live your dream; conclude everything you want to do, before you supposedly die. That’s what’s so great about my life.”

David’s strength and enduring spirit to fight this disease leaves one in awe. When thinking about the way in which he tackles each step along his journey with HIV, I wonder if his strength perhaps rests on having done so much of it alone. Has his silence in some way been the powerful mechanism which has fuelled his enduring triumphant spirit?

Conclusion

When looking at the above it is clear that a pre- and post-HIV narrative emerges. These two narratives are punctuated as separate by David finding out that he was HIV positive. The former comprises his family and the themes that emerged in their history; the latter is David’s story of silence and living with HIV. What is interesting to note is how the themes in one are mirrored in the other. These connections and this mirroring will be explored in the concluding chapter.

CHAPTER 5

WEAVING TOGETHER THE STRANDS

The road not taken

Two roads diverged in a yellow wood,
And sorry I could not travel both
And be one traveller, long I stood
And looked down one as far as I could
To where it bent in the undergrowth;

Then took the other, as just as fair,
And having perhaps the better claim,
Because it was grassy and wanted wear;
Though as for that the passing there
Had worn them really about the same,

And both that morning equally lay
In leaves no step had trodden black.
Oh, I kept the first for another day!
Yet knowing how way leads on to way,
I doubted if I should ever come back.

I shall be telling this with a sigh
Somewhere ages and ages hence:
Two roads diverged in a wood, and I--
I took the one less travelled by,
And that has made all the difference

By: Robert Frost (Frost, n.d.)

I set out on this journey believing that my preparations, studies and knowledge about HIV/Aids would provide some kind of map for me. Based on that I anticipated a certain direction, but nothing could have prepared me for where the journey took me and what it revealed, about myself, about living with HIV/Aids and about the tenacity of the human spirit. The path it took me on was undeniably the road less travelled.

In this chapter, I endeavour to weave together the many strands that comprise this journey; and through this, a preliminary ending will be punctuated, though the journey continues.

The Binding Thread

The theme of silence underpins and connects the three narratives in this text: David's, my own, and the emergent co-constructed narrative. Silence reverberates throughout as a theme in David's story and appears to serve many functions. For one, it conserves and protects both him and his story. When reflecting on his life one must conclude that perhaps a person can only endure one inversion of his or her reality in a lifetime – discovering his HIV status was his – and that he needs the silence around his illness to protect him from a second inversion of his reality. Learning about his HIV status can be described as an internal inversion of his narrative, whereas disclosing his status to a threatening world could be conceived of as a possible external inversion. Silence maintains sameness in David's HIV/Aids narrative, whereas disclosure would entail a complete re-edit.

On an implicit level, the theme of silence manifests in David's family as well. I believe that his silence must have continually shifted his sense of relatedness within his family, as it changed aspects of his identity and belonging. Perhaps explicitly things have continued as before, as the patterns of relatedness appear to still be the same, but beneath the surface things have shifted. Thus the relatedness can be conceived of as a pseudo-sameness or pseudo-togetherness. In considering this, I wonder if this is not common to most families – that there are certain secrets that serve a function in that they need to remain secret for the family's patterns and relationships to be maintained. In this way David is conserving his family sameness by carrying a secret which, if disclosed, would differentiate him from them, a secret that may shatter an intrinsic and defining rule of this family.

Lastly, the role of silence in David's life can be understood from another vantage point. Silence created a solitary path and ensured that David only had himself to rely on for many years. His silence about his HIV status can be seen as the powerful mechanism which has allowed his enduring triumphant spirit to grow, and which has in turn carried him through the most difficult, dark pathways of his journey.

In speaking to me, David took a momentous step towards breaking the silence by disclosing his status to me and revealing some of the most private aspects of his story. The effects of our dialogue echoed differently for David and for me. David reflects on his experience: "Well what can I say, I never really thought that I would be able to chat to a 'stranger' so freely regarding my condition and life history, and it made me feel so good too. Perhaps, with time, I'll be able to speak to that crowd of a thousand people or more!"

Exploring the role of silence in David's life has shed light on quiet and unspoken avenues in my own life story. David's courage to allow me to listen to his silence has freed and encouraged me to question the silenced pathways of my own journey, and as such, has shed *light on my own narrative of silence. It was in meeting David and in him allowing me the privilege to deconstruct his story that I began to grapple with my own silence.*

There are numerous overlapping themes that are mirrored in David's and in my own story. For one, I have discovered that silence in my life also functions as protection – mostly as protection from being different within my own family. In this way it serves to conserve the family sameness. As in David's case, my silence enables me to abide by familial rules and in so doing keeps the connections of relatedness in my family intact. Moreover, I realise that this is echoed in the individual stories of the other members of my family too, as they undeniably also walk a dual path of sameness and aloneness. Until now I had not confronted or understood why I have chosen to keep certain parts of my story to myself.

In reflecting on the process, I realise that David has opened my eyes to the role of silence as a facilitator to maintain equilibrium in my family of origin, but moreover, it has ignited an ongoing exploration into my own family's implicit patterns and how these reverberate in my life story. What I have learned thus far is that silence in some way defines relationships; it moulds our conceptualisations of the other in a certain way, and in so doing it can create a particular reality. In this way my own silence can be understood as attributing to my definition of who I am in my family; it constructs particular descriptions of who I am through their lens, and it contributes to the creation of our family reality.

Finally, this journey has allowed me to take the road less travelled in areas of my own life as well.

After reflecting on the theme of silence, I am left wondering about the silence between me and David. I am left wondering whether my silence when first meeting him was born out of pity I felt for him, being HIV positive, and whether it stemmed from the genuine surprise which I experienced during our first interview when I discovered how well he was coping, despite his dreaded illness. And from David's side: Did he silently question my intentions? Was he concerned that I was looking at him as an object of interest, something I was curious about? Whatever silence between us may have been, the poignant realisation is that it existed and informed a particular reality that was created in our initial meeting. With time, our dialogue and our journey together unquestionably shifted many of my preconceptions that emanated from the silence. I can only hope that this experience resulted in a similar shift for David.

Connecting Mirroring Themes

The themes which I punctuated in David's personal and family story emerge from my subjective interpretations and are seen through my lens. They represent the process of deconstructing his narrative and reconstructing it to create a new edit of his story. This edit is simply another version; a version that is informed by both my own and David's meaning systems. I recognise that I stand apart from David's journey, but in being invited to walk for a short while along his path, I in some way form a part of a new co-evolved chapter. In this way I took both a meta- and participatory position, punctuating certain meanings from a meta-view, while at the same time participating in the dialogue from which these meanings emerged.

There are numerous themes that emerge in both David's family and personal stories, which provide the connecting thread along David's path. His own meanings and epistemology were created within the context of his family, and as such the overlapping themes provide a further description and furnish a richer understanding of his personal journey. In addition, certain connections can be further expanded to the broader social context.

During David's upbringing everything centred on the family and there appears to have been a strong and somewhat impermeable boundary around them, where information was allowed into the family system, but what happened within the family was more private. David too is quite boundaried in the sense that he has maintained a profound silence that manifested in perhaps a more distant connection with others. Growing up, David's family also lived during a time of war, which had a significant impact on their lives and has reverberated into his own life. Times of war are indicative of a great threat that exists "out there". Perhaps for David the remembrance of these times is not too dissimilar from the ongoing threat of stigmatisation, for him his ever-present "out there". David has learned to carry on, amidst the effects of such an enduring external threat.

There are other implicit rules that defined David's family of origin. One is the sense of belonging that the familial boundary created. The way in which they were able to create such a sense of belonging within the nuclear family, despite being uprooted numerous times, must have enabled David to create this same sense of belonging within the parameters of his own life. Like the two generations before him, David, at pivotal times, uprooted and re-established himself. One example is his move to Cape Town when he found out he was HIV positive. He has succeeded in carving a unique place of belonging for himself in this world – his home, work, guest house are facets of this – it is here where he belongs, where his heart is.

Another implicit rule of his family is that they were always different. The notion of us and them not only affirmed the boundary, but enabled an acceptance and endurance for being different. HIV has made David different from mainstream society. However, he carries with him a deep acceptance of himself, which is balanced by an appreciation for difference on the one hand, and by a deeper belief that HIV does not necessarily differentiate him as different on the other. I think on some level his enduring silence stems from a need to maintain the latter.

Pre- and Post-narratives

In a country with roughly 5.5 million people living with HIV/Aids one man's story has completely changed how I conceptualise, language and understand this disease. My simplistic one-dimensional depiction of HIV/Aids, as a mere statistic, has profoundly shifted to a complex, richer one, as I have expanded my description to add many new layers of meaning.

It was only in coming face-to-face with one man's experiences of HIV that this personal growth was made possible. Being confronted with HIV/Aids in this way has created a pre- and post-HIV/Aids narrative for me – the former comprising facts and knowledge that existed out there; the latter the result of the implicit connection and learning that was birthed from the knowledge I gained through personal experience.

David too portrays a pre- and post-HIV narrative, which emerged through his personal experience of having the disease. His pre-HIV story comprises his life before that day in 1986. His life was on a particular course; in an instant it shifted direction and a new journey began for David. All his meaning systems shifted: his understanding of HIV/Aids, his conceptualisation of his family and their connectedness, his place of belonging in this world and within his family, his identity and sense of self, and the meaning of life. Over time David re-edited his personal narrative. He created vast new meanings that enabled a redefinition of his past beliefs and pre-HIV story, in a way that included this new reality. His story is testament to the idea that it is within the human capacity to survive such a profound re-edit of one's story. What I believe my journey with David demonstrates is that profound shifts and re-edited meanings are made possible only when another is invited to share a glimpse of such a journey.

My evolving understanding of the illness was birthed by David's and my co-created reality about HIV/Aids. One the one hand, HIV/Aids represents the socially constructed beliefs about the illness, including the unwavering dogma that maintains its position as an epidemic of stigma. It is undeniable that the reverberations of stigmatisation and discrimination have a cumbersome effect on both people living with HIV/Aids and on HIV negative members of this society. However, on the other hand, HIV/Aids also represents a life; a person who does not succumb to the frightening power of the disease, but who emerges triumphantly despite their ongoing struggle with the entrenched, internalised societal discourse regarding HIV/Aids.

By allowing me into his world, David enabled me to confront many of my previously held ideas regarding HIV/Aids. In the process my largely unconscious beliefs emerged and were challenged through the telling of his story. Most profoundly, this process has destigmatised HIV/Aids for me, but moreover it has ignited a flame within, to share this experience and learning. This is beautifully captured by the following poem:

To part a curtain
My continuing passion is to part a curtain.
That invisible shadow that falls between people,
The veil of indifference to each other's presence,
Each other's wonder,
Each other's human plight.
By: Eudora Welty (as cited in Wheatley, 2006, p. v)

The unique learning that this journey has brought me makes me wonder about the value of ever-increasing information, statistics and knowledge about HIV/Aids. Does it truly have the power to shift discourse on HIV/Aids in this country? My experience has facilitated such a profound shift from my previously held conceptions that I believe the answer is no. It is primarily in the meeting of, and in the listening to, the experiences and voices of the other that our own descriptions, discourses and realities can shift. Let us share our stories and walk the road less travelled; let us create a South African pre- and post-HIV/Aids narrative.

Final Thoughts

This research punctuates a beginning, an ending and a continuing path. It has given HIV/Aids a voice that I can begin to touch and hear and know. It has enabled connection, as my experiences and reflections have spanned the bridge between the construct of HIV/Aids and one man’s experiences of living with HIV. Furthermore, it has been a profound experience of discovery and I am privileged to have been invited to become a part of such a personal journey. I hope that I may continue to walk the path that bridges the disconnection that HIV/Aids creates; moreover, that by walking in the silenced pathways of others I may continue to weave the riches of other’s experiences into the tapestry of my life.

Lastly, I hope that future research on this topic will give credence to new voices that until now have remained silent; in addition, that future research may facilitate a deeper understanding of HIV/Aids by listening to and retelling the stories of the many silenced voices.

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APPENDIX I

Consent Form – Participant Copy

My name is Ilse Robbertse, and I am registered as a Masters student in Clinical Psychology at the University of South Africa (UNISA). As part of the Masters Degree in Clinical Psychology, I am required to complete a dissertation. My research will be focusing on the untold stories of HIV/Aids in South Africa. I am interested in exploring people's personal experiences and attitudes around being infected by and living with HIV, as well as that of those close to them, and society around them. I require an individual who is willing to participate in my research study, who would be prepared to discuss his/her own personal experiences in relation to this. My hope is that this research may benefit the participant, though this cannot be guaranteed. Furthermore, I hope that this research may be helpful to professionals who work with HIV positive individuals and to lay people.

The interview will be available to my supervisor, Prof Ricky Snyders, and to an external examiner. Once completed, it will also be available in the UNISA library. In order to protect your anonymity, no personally identifiable details will be included. I would like to include biographical information and a genogram, however, names and places will be changed to insure your remain anonymous. Furthermore, your name will not be recorded anywhere on the transcribed interview.

A series of interviews will be required. These will be scheduled well in advance at your convenience. Please try to be as open and honest as possible in telling your story. Some of my questioning may be of a personal and/or sensitive nature; I will also ask some questions that you may not have thought about before, and which involve thinking about the past or the future. Even if you are not absolutely certain about the answers to these questions, try to think about them and answer as best you can; this is your story and as such there are no right or wrong responses to any of these questions.

Your participation in this research is entirely voluntary. If you do not wish to answer a question or explore a particular topic further, you may refrain from doing so. Even if you agreed to participate initially, you may stop at a later stage and discontinue your participation. If you refuse to participate or withdraw at any stage, you will not be prejudiced in any way.

Furthermore, if at any point during our discussion you fell saddened or upset by a question, we can stop the interview and discuss it. There are also people to whom I can refer you who are willing and able to talk it through with you if you so wish. If you need to speak with anyone at a later stage, a professional person, Dr Sonja Snyman, who is a Psychotherapist, can be reached at the following telephone number (011) 880 7645.

I may require (an) additional interview/s at a later stage, and may also like to discuss my findings and proposals around the research with you, once I have completed my study.

If you have any other questions about my study, please feel free to contact my supervisor, Prof Ricky Snyders, at the University of South Africa, at Snydefja@unisa.ac.za / 012 429 8222.

APPENDIX II

Consent Form – Researcher Copy

I hereby agree to participate in the research regarding the untold stories of HIV/Aids in South Africa. I understand that I am participating freely and voluntarily. I also understand that I can stop this interview at any point should I not want to continue and that this decision will not prejudice me in any way.

The purpose of the study has been explained to me, and I understand what is expected of me.

I understand that this is a research study, which may or may not necessarily benefit me personally. I have received the telephone number of a professional person to contact should I need to speak about any issues that may arise as a result of this interview. I understand that this consent form will not be linked to the research documentation, and that my personal information will remain confidential. I understand that, if requested, feedback will be given to me on the findings of the completed research.

Additional consent to audio recording: In addition to the above, I hereby agree to the audio recording of this interview for the purposes of data capture. I understand that no personally identifying information or recording concerning me will be released in any form. I understand that these recordings will be kept securely in a locked environment. I further agree that the interview may be transcribed by a trustworthy individual who will sign a confidentiality agreement.

Signed at ___________________________, on this ____ day of _________________ 20___

___________________________________	___________________________________
Name of participant	Name of researcher
___________________________________	___________________________________
Signature of participant	Signature of researcher