

HIV as an Internal Object:

The subjective experience of HIV infection in women on ARVs.

By

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Dedication

Dedicated to those in my life who have made it through the storm this year. We are all warriors and I have witnessed true bravery.

Acknowledgement

From the bottom of my heart, I thank:

- Dr. Katherine Bain for her endless support, time, and unfaltering ability to keep me cohered. My thanks will never be enough for all she has done.
- The women of this study. I thank them for their honesty and time, and am in awe of their strength. I thank them for teaching me.
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Abstract

HIV/AIDS research has proven crucial in an effort to prevent and manage this epidemic. However, there is little research being done in an attempt to understand the internal worlds of those living with HIV/AIDS. The purpose of this research was to begin to explore the relationship that exists between the person living with HIV/AIDS and the virus, as an internal object, inside them. This study focused on 6 women who were on Anti-Retroviral Medication (ARVs), and who have been diagnosed for at least one year. The participants' mental representations of the virus as an object inside them was explored, as well as how they experienced and viewed the triangular relationship that exists between themselves, the HI Virus, and the ARVs. This exploratory research utilised a qualitative framework in order to understand and explore these relationships and perceptions, with psychoanalytic theory being used a lens through which to view the data that emerged. In depth semi-structured interviews were conducted with the participants, and the corpus of data was analyzed using a thematic content analysis. In addition, the participants were asked to draw the virus inside their bodies. These were analyzed using a technique devised by Paola Luzzatto (1987) in a study exploring the internal world of drug-abusers. For the purpose of this study, a variation of the same art therapy technique was used in that the participants were asked the 'draw the virus in their bodies'. Whilst the drawings allowed for insight into the internal worlds of the participants, the drawings were also used as a point of departure. For most of the women, HIV was drawn using a red crayon, whilst the ARVs were drawn in either yellow or green. As depicted in the drawings, post diagnosis the HIV/red seemed to cover most of the body, but later when the ARVs/green was added, more of a balance was achieved. Results show that for these women, HIV was often perceived as dangerous and criminal, whilst the ARVs were often associated with security. From the perspective of Kleinian theory, the perception of the HIV and the ARVs seemed to be dependent upon the position from where they were functioning: either a paranoid-schizoid or a depressive position.

Keywords: HIV, AIDS, ARVs, internal object, object relations theory, HIV-related stigma, psychoanalytic framework, South Africa, mental representations, visual representation,

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Chapter 1: Introduction

Due to the worldwide predominance of the Human Immunodeficiency Virus (HIV) epidemic, a large number of organizations release annual information to contribute to the existing corpus of data. “Sub-Saharan Africa remains the region most heavily affected by HIV. In 2008, sub-Saharan Africa accounted for 67% of HIV infections worldwide, 68% of new HIV infections among adults and 91% of new HIV infections among children. The region also accounted for 72% of the world’s AIDS-related deaths in 2008” (UNAIDS, 2009, p. 21). Due to the aforementioned statistics, HIV/Acquired Immunodeficiency Syndrome (AIDS) research has proven crucial in an effort to prevent and manage this epidemic. However, there are still areas that are largely unexplored, and there is relatively little research being done in an attempt to understand the internal worlds of those living with HIV/AIDS. Since the roll-out of antiretroviral (ARV) treatment in South Africa, research has begun to explore the role of these ARVs in the lives of HIV-positive individuals (Kremer, Ironson, Schneiderman, & Haut zinger, 2006); however, further research in this area is required.

1.1 Aims

To explore women on ARV’s mental representations of the HI virus and the ARVs in their bodies, and their subjective experience of that relationship, using a psychoanalytic framework.

1.2 Rationale

This exploratory study served several purposes and aimed to contribute to the body of literature on HIV/AIDS research. Firstly, whilst there was a great deal of research surrounding the HIV epidemic, there was very little research that existed to help explain the internal psychic relationship between the person and the virus. The limited research that does exist seemed to focus on the effects of the HI virus on external relationships, as opposed to the internal relationship (Goggin, Catley, Brisco, Engelson, Rabkin, & Kotler, 2001). A greater understanding of the internal relationship may yield greater insight into the experience of those living with the HI virus. Secondly, this study aimed to explore this relationship from a psychoanalytic perspective, which might be beneficial in terms of assisting therapists working

from this perspective to understand and assist patients to manage this relationship. A previous study by Blechner (2000) has:

...provided an in-depth view of the heights of courage and the depths of despair experienced by therapists who treat patients facing imminent death. The cause of death is AIDS, and the book accomplishes its mission, that is, to show that a psychoanalytic-psychodynamic perspective can be adapted and used to treat HIV/AIDS patients, so that their psychological suffering and pain are minimized (p. 190).

However, whilst this study showed how a psychoanalytic perspective can be used to treat HIV/AIDS patients, it did not provide a discussion regarding HIV-positive individuals' experience of the virus in their bodies from a psychoanalytic perspective.

The reason this study has focussed on women is due to the prevalence and incidence of HIV/AIDS among women in South Africa. "In sub-Saharan Africa women account for approximately 60% of estimated HIV infection...Women's vulnerability to HIV in sub-Saharan Africa stems not only from their greater physiological susceptibility to heterosexual transmission, but also to the severe social, legal and economic disadvantages they often confront" (UNAIDS, 2009). Hence, this study hopes to contribute to the understanding of this previously marginalized population's experiences.

A previously conducted South African study used a combination of social constructionist theory and psychoanalytic theory to explore the stigma that surrounds HIV amongst infected women (Rohleder & Gibson, 2006). The study explored how women experience and deal with AIDS stigma under conditions where they have little formal support. The analysis suggested that the women drew on negative social discourses around HIV, which were then internalized to become part of the self. This study, performed by Rohleder and Gibson (2006), adopted a social constructionist framework, but posited that psychoanalytic theory may be a useful framework through which to explore HIV/AIDS experience, as it will provide an understanding of how these negative representations are experienced emotionally and will also show how those living with HIV attempt to protect themselves from the anxiety associated with a stigmatized identity. Thus, increasing HIV/AIDS research is needed that uses a psychoanalytic framework and although this study was firmly situated within a psychoanalytic framework, it has incorporated social constructionist theory allowing for the consideration of the influences of larger societal

discourses on the experiences of the participants.

The existing literature on HIV/AIDS also seemed to be predominantly quantitative in nature (Simoni & Ng, 2002). Hence, this study hoped to contribute from a qualitative perspective and utilised a qualitative framework in order to understand and explore the relationships between HIV, ARVs, and the infected individual, from their perspective, and perceptions, with psychoanalytic theory being used a lens through which to view the data that emerged.

Additionally, Anti-Retroviral (ARV) medication is an emerging area of study and is currently a relatively unexplored field. For example, in a study by Kremer et al. (2006), the decision making process regarding ARVs was considered. However, the internal relationship between the person living with HIV and the ARVs themselves is not considered, nor is the mental representation of the ARV as an internal object. Also, it is the external factors that are predominantly the focus of the study. To elaborate, instead of the internal world being explored, the participants CD4 counts, quality of life, knowledge about resistance, worldview, and drug resistance were looked at as reasons either to take or not to take ARVs.

In sum, this study was conducted with the overall aim of trying to better understand the relationship between the person living with HIV, the virus that inhabits her body, and the ARVs, from a psychoanalytic perspective.

1.3 Research design

This brief discussion of the research design is merely an overview of the methods used for this study and a more comprehensive discussion can be found in Chapter Four. This research has used qualitative research methods. “Qualitative research aims to address questions concerned with developing an understanding of the meaning and experience dimensions of humans’ lives and social worlds” (Fossey, Harvey, McDermott & Davidson, 2002, p. 717). Due to the fact that this research aimed to explore the participant’s subjective experience of the relationship that existed between themselves, the HI virus, and ARVs, a qualitative design was most appropriate. In addition, qualitative research was suitable for this research as the information yielded from the transcribed interviews yielded rich data that allowed for in-depth analysis and interpretation of the participant’s perceptions. This research continuously aimed to authentically convey the

participants' perspectives and subjective experience, as understood by them. However, this study fitted the criteria for both an inductive and deductive paradigm. As a result of the qualitative research design, this research fell under the interpretive paradigm. This paradigm places "emphasis on seeking understanding of the meanings of human actions and experiences, and on generating accounts of their meaning from the viewpoints of those involved" (Fossey et al., 2002, p. 718-720). Furthermore, since it was the participants' own subjective experience that was being valued most highly, it was the interpretive paradigm that this research fell under. It is an inductive approach, as it focused on building themes in an upward sense. However, after collation, thematic analysis and presentation of the data, these themes were viewed and interpreted through a psychoanalytic lens and discussed in this manner. Hence it was at the same time deductive. Deductive or theoretical thematic analysis tends to be driven by the researcher's theoretical stance (Braun & Clarke, 2006). Hence, for this study, the researcher viewed the data from a psychoanalytic stance.

1.4 Theoretical framework

1.4.1 Psychoanalytic theory

Once again, this discussion of the theoretical framework is merely an overview and a more comprehensive view can be found in Chapter Three. This study has explored the relationship that exists between the person living with HIV/AIDS, the ARVs, and the virus, as internal objects. Psychoanalytic theory was consulted and more specifically, object relations theory (ORT) was used as a lens through which to view the data that emerged.

As explained by Hamilton (1988), over and above our external relationships between ourselves and others, we also have relationships that reside within us. These are not just "static images, but rather, powerful influences on how we feel about ourselves and relate to others" (Hamilton, 1988, p. 3). The first relationship exists between the infant and the parents, where the infant sees itself as undifferentiated from the parental unit. In order to protect and preserve this self-parent unit, problems and difficulties are seen to exist as outside of the dyad (Hamilton, 1988). This process of internalizing and externalizing continues as the infant develops, as the infant takes in certain parts of relationships and assimilates them into their internal world. Object relations theory is the study and exploration of these internal and external relationships and it is the

outcome of these explorations that may help in understanding the mental states of both healthy and ill people.

The title of this study 'HIV as an internal object' is a play on words. HIV was looked at in both a literal and figurative manner, with the actual virus as an independent or separate object within the body being explored, as well as the mental representation of HIV or how the person views the object based on previous relationships. The second and more figurative exploration was informed and supported by Melanie Klein's theory of object relations.

While "Freud first elaborated how identification processes influence the form of adult association... this was elucidated further by Klein's concept of projective identification" (Nuttall, 2000, p. 213). Hence, it is of relevance to this research to provide background to Klein's concept of object relations, as this construct will help to illustrate how internal objects come to be negotiated. According to Rohleder (2007):

Klein (1959) talks of defensive positions which originate in infancy. In the paranoid schizoid position the infant splits its experience of the 'good', nurturing mother that is loved, as separate to the 'bad', frustrating mother that is hated. The infant's early interaction with the primary object consists of both gratifying moments and frustrating moments. When the infant's needs are fulfilled, the mother is experienced as nurturing and loving. When the infant's needs are not fulfilled, the mother is experienced as persecutory. In order to maintain the good experience of the nurturing mother, the infant separates the 'good' mother from the 'bad'. Through the unconscious defence mechanism of splitting, the good experiences are taken into the self, and bad experiences are projected outwards (p. 405).

Therefore, according to Kleinian theory, from infancy the first object a person encounters is the mother's breast, which is viewed as both good and bad. These positive and negative perceptions are either introjected or projected, and assist in the formation of the person's internal world.

Thus, early object formation impacts upon the mental representations that a person draws upon later in life. During the second quarter of the infant's first year the intellectual and emotional development changes the way the infant relates to the world. The infant no longer relates to its objects as part objects, as in the good breast and the bad breast, but now is able to relate to the object as a whole (Klein, 1952). In other words, the infant is now able to relate to the mother as a whole and no longer as a part object. In this position there is a change in the nature of the defences that are present. Split feelings of 'love' and 'hate' are now able to come together. This more

reconciled position is known as the depressive position. Ambivalence is now felt towards the complete object. This leads to depressive anxiety and guilt and need to make reparation (Klein, 1952).

In relation to HIV, previous research has found splitting to be a common defense mechanism that is utilized. The first occurs between the 'self' and the 'other'. For example, for the individual who is uninfected with HIV, the 'self' is seen as 'good' and the 'other', the person living with HIV is 'bad' and is therefore rejected. Hence, the 'self' remains the pure primary self that does not have HIV, and in order to defend this pure and uninfected 'self' the 'other' becomes those that are infected with the virus (Rohleder, 2007). Other research, proposes a slightly difference concept whereby the 'self' is the one who is infected with the virus, who is responsible for knowing their status and thereby good, and the 'other' refers to those who probably have a virus but are unaware of their status and are therefore bad (Rohleder, 2007). Thus, a defense mechanism is employed that helps to preserve the 'self'. In the latter concept, even when the 'self' is now 'impure' due to being infected with the HI virus, an othering process still occurs whereby the 'others' are seen as bad due to their ignorance. What this research will entertain and explore is the notion of the primary self being the 'self' and the 'other', being the HI virus that is living inside the primary 'self's' body. Thus, the internal relationship will be explored as to what occurs between these two entities. To elaborate, the situation now exists where the 'self' is preserved as good, but the internal body is now tainted by the HIV: the negative internal object.

In addition to Kleinian theory, this research also utilised Bion's theory of thinking. What is of particular interest is the idea of being able to think about the virus. According to Bion, the ability to think one's own thoughts is crucially important, as is the ability to think about one's own experience, to think about others' experiences, and to rise up against one's 'personal internal resistance to acknowledge painful realities' (Ivey, 2009, p. 113). Bion's concept of 'thinking' is not referring to the frequently used term associated with cognitive processes of the brain, but rather to the process by which an individual attempts to know himself or another. According to O'Shaughnessy (1981): "His [Bion's] concern with thinking is as a human link, the endeavour to understand, comprehend the reality of, get insight into the nature of, etc., oneself or another. Thinking is an emotional experience of trying to know oneself or someone else" (p.

81). Klein laid a crucial foundation for this view by differentiating between “intrusive curiosity, stimulated by a voyeuristic need to ‘know’ in order to master and control, and a more enlightened desire to understand; something more akin to a thirst for knowledge, in the interest of growth rather than of mastery” (Waddell, 1998, p.102). It is this interest in growth that differentiates the emotional knowing characteristic of a K link from the desire to fill the intellectual storehouses of the mind with knowledge as a commodity, enabling one to avoid personal meaning and growth (Waddell, 1998). In contrast to K, Bion allocated the symbol –K, which he conceived of as a resolve not to know. According to Bion (1962) “...an emotional experience that is felt to be too painful may initiate an attempt either to evade or modify the pain according to the capacity of the personality to tolerate frustration” (p. 48). According to Bion (1962) when there is “a need to be rid of emotional complications, of awareness of life and of a relationship with live objects” (p. 11), knowledge of painful internal and external reality is evaded. Thus in reference to this study, Bion’s theory is helpful in understanding the way the women are able or unable to think about the HIV in their bodies.

1.5 Brief discussion of following chapters

While Chapter One provided a brief introduction to this study, Chapter Two provides an introduction and overview to the field of HIV/AIDS, with a focus on the lives of women living with HIV as well as the stigma they experience. Following on from that, Chapter Three provides an overview of the theoretical concepts that this study has used as a means to understand the internal worlds of those living with HIV. Chapter Four presents a description of the research process of this study, including the research method, data gathering process, and the analysis procedures. In Chapter Five, the results and findings of this study are presented, and quotes have been included so as to present the results in as truthful a manner as possible. Whilst Chapter Five has little interpretation of the results, Chapter Six presents a discussion of the findings of this study by integrating the themes and attaching them to theory. Finally, Chapter Seven details the recommendations for further research, the limitations of the study, and a summary of the findings.

Chapter 2: Literature Review

2.1 Introduction

In order to explore the internal worlds of those living with HIV, it was important to first examine the existing literature surrounding HIV and AIDS. This chapter will discuss the topic of HIV/AIDS under several headings. Firstly, HIV and women will be looked at, followed by HIV and stigma. The role of the ‘other’ and HIV will be explored, followed by a brief review on the existing literature surrounding ARVs. Finally, the link between the mind and body will be investigated, with the role of culture in this connection being a central focus.

2.2 HIV/AIDS

Overall, the majority of HIV/AIDS research seems to focus primarily on the external worlds of the person living with HIV, and in turn, does not explore the internal worlds. Thus, this study has explored the meaning of illness, rather than what the illness means from an external perspective. “According to Kleinman, illness meanings reflect people’s personal experiences and explanations of their conditions. Illness meanings are dynamic, situated, and contingent (Kleinman, 1988). They are intertwined with the messiness and complexity of life, and are constructed as illnesses are lived” (Scott, 2009, p. 455). While research on stigma has covered HIV-positive women’s experiences in relationships with significant others and the public (Campbell, Foulis, Maimane, & Sibiya, 2005), this study aimed to focus on HIV-positive women’s relationships with the virus and the ARVs they are taking. This section will address some of the existing literature and several factors that may affect or mould this internal relationship and that are relevant to the participants involved in this study.

2.2.1 HIV and Women

Women living with HIV endure a vastly different experience than men living with HIV. “In South Africa, black women generally occupy the lowest rungs on the hierarchy of social, economic, and political power. Women are also the group most affected by HIV and AIDS...Black South African women with HIV/AIDS are likely to be subject to multiple forms of stigmatization that create for them a ‘spoiled identity’” (Rohleder & Gibson, 2006, p. 27). This ‘spoiled identity’ is as a result of several factors and the stigma that the women experience is multifaceted. For example, “Individuals who are divorced, separated or widowed tend to have

significantly higher HIV prevalence than those who are single, married or cohabitating, with divorced or widowed women experiencing especially high prevalence” (UNAIDS, 2009, p. 22). Furthermore, it is quite common for this abandonment to stem from the women’s HIV status, through either being abandoned due to her positive status, or from having lost her spouse due to an AIDS-related illness. Thus, black women are initially stigmatized due to the HIV diagnosis, but the stigmatisation may continue as the women are then abandoned as a result of their status.

Due to the fact that women are the recipients of the stigma mentioned above, as well as due to the significantly higher HIV prevalence in women, this research has focused on women. The HIV/AIDS pandemic has been undeniably feminized, as nearly 57% of all infected adults are women and 75% of young people infected are girls (UNAIDS 2004). According to an American study that was designed to expand upon the understanding of the women’s psychosocial experience of being HIV positive, the women experienced both positive and negative symptoms following their diagnosis. Some women were able to harness the diagnosis and convert it into a rousing mechanism for positive change. “Common negative experiences included physical symptoms, a limited life span, alienation, and stigma” (Goggin, Catley, Brisco, Engelson, Rabkin, & Kotler, 2001, p. 80). While the aforementioned study gave a comprehensive discussion around the life changes experienced by women due to an HIV-positive diagnosis, the current study hoped to deepen this understanding by providing a discussion of HIV-positive women’s intra-psychic experiences and changes.

There are several reasons as to why this research has focussed on women, and particularly women in Africa. Current and existing research tends to centre primarily on men, and is predominantly centred on high-income countries (UNAIDS, 2009). This is due to a focus in male to male transmission. Secondly, in African culture, women tend to assume a lesser and inferior role in society (Rohleder, 2007), so their perspectives are largely viewed as unimportant and often ignored. Hence, this research hoped to contribute towards a change in this focus. Finally, women are the focus of this study as they are the group that is most largely affected.

2.2.2 Stigma and HIV

Stigma and HIV are closely intertwined, especially so in the South African context. Stigma is highly relevant from a healthcare perspective as well. Stigma increases the stress associated with

the illness, it contributes to secondary psychological and social morbidity, and it thereby affects quality of life and physical well-being (Fife & Wright, 2000). Being diagnosed with HIV maybe traumatic in itself, but living with HIV/AIDS in a South African context is fraught with stigma.

The origin of these stigmas is perhaps culturally rooted:

Attributes that produce stigma are not inherently deviant, but derive from the culturally embedded meanings of a particular historical period or cultural milieu. In the case of HIV/AIDS, infected persons are generally perceived in negative social terms and marginalised as the carriers or hosts of a deadly transmissible disease...Stigmatising ideas about HIV have a powerful hold on society because they are often based on pre-existing stereotypes and prejudices...resulting in AIDS often being framed within a moral concept of blame, responsibility and deservedness (Visser, Makin, Vandermael, Sikkema, & Forsyth, 2009, p. 197).

Thus, HIV positive individuals are sometimes judged to have contracted the disease due to their own behavior; behavior that is felt to already be culturally prohibited. There are a number of factors that affect stigmatising beliefs about HIV/AIDS, and in South Africa, previous studies have shown that people who are “poor, uneducated and lack basic literacy skills tend to stigmatise more than the more affluent and educated” (Visser et al., 2009, p. 197).

Susan Sontag (1991) has explored the connection between sickness and morality. “Those who are viewed as diseased, she argues, are often perceived as reaping the consequences of their immoral behaviours, just as those who are seen as ‘immoral’ are believed to be inherently pathological. The stigma that is attached to diseases such as HIV/AIDS delineates the immoral infectors from the innocent victims, the promiscuous from the pitiful, defining the former as agents of infection and the latter as subjects of empathy”(Brijnath, 2007, p. 378). “The use of particular metaphors, imageries and language defines not only how we view AIDS in Africa but also Africans who live with AIDS” (Brijnath, 2007, p. 372).Some of these metaphors will be elaborated upon below.

In the study by Visser et al. (2009), approximately two thirds of the respondents perceived most people in their community to judge people with HIV negatively and to distance themselves from people with HIV. Visser et al. (2009), see various reasons that can be given for this difference. “A person typically compares him/herself to others with a tendency to consider the self in a more positive light as being more compassionate and considerate, while presuming others to be less

so”. Another explanation is that people might overestimate or generalize the negative stigma of others in the community.

A study conducted at the University of KwaZulu-Natal, explored the stigma that surrounds HIV/AIDS in South Africa (Bhana, 2008). Whilst this research focused on children, it served to show how stigma becomes embedded within the individual. This study explored how HIV-related stigma is viewed by seven- and eight-year-old white South African children. The study, which used elements of ethnographic and interview data, showed how “young children’s responses to HIV and AIDS are inscribed within popular accounts of contagion and articulate gendered, sexual, raced and classed discourses in South Africa” (Bhana, 2008, p. 725). The paper detailed how children both reject and accept the power inequalities, but also display care and concern for others infected with HIV and AIDS (Bhana, 2008). Results of this study showed that the children viewed “HIV/AIDS as a ‘catchy’ disease” (Bhana, 2008, p.730).

Further evidence of the stigma is illustrated by a study performed in Cape Town. The narratives of the women interviewed showed their contempt for their HIV status as they referred to their “spoiled identity” (Rohleder & Gibson, 2006, p. 25). Hence, according to the literature, as well as the narrative accounts, there are several prominent themes that pervade the HIV/AIDS discourse. As noted in Rohleder and Gibson (2006), several metaphors surrounding HIV/AIDS are prevalent. Susan Sontag (1991) has argued that AIDS has emerged as a disease “whose charge of stigmatization, [and] whose capacity to create spoiled identity, is far greater” than that of other diseases (p. 101). Sontag (1991) goes on to comment that the socially constructed meanings describing HIV/AIDS centre on AIDS being a plague, evil, and sinful (Sontag, 1991).

As cited in Rohleder and Gibson (2006):

Gilmore and Somerville (1994) also discuss the powerful metaphors, which are used in interpreting the meaning of HIV and AIDS. These metaphors are socially constructed meanings, which are used by society to interpret and understand the disease and those infected with the disease. They note seven interacting metaphors including HIV/AIDS as death; as punishment; as crime; as war; as otherness; as horror; and the HIV sufferer as villain (p. 26).

As a result of the stigma experienced by those living with HIV, a sense of isolation perhaps occurs. Ironically and perhaps unfortunately, it is a sense of connection that some report assist in coping with HIV. A participant from a panel discussion reported how it was this sense of

connection that allowed for him to regain a resolve to survive. This involved reclaiming his stolen power from the virus and reintegrating it into his sense of self. “He recognized that the virus had the capacity to kill him but that it would be on his own terms. These insights allowed him to make a transition from despair to hope” (Gosling, 2008, p. 265).

For the purpose of this study, these stigmatized metaphors are important as the way society views HIV/AIDS may impact how the person themselves views the virus inside them. Judge Edwin Cameron in an interview, emphasized that stigma had both external and internal dimensions, with the external dimension manifesting in discrimination against and ostracism of persons living with AIDS, sometimes culminating in extreme violence, and the internal dimension consisting of feelings of shame, contamination and self-blame that someone with HIV or at risk of HIV feels within him- or herself (Gosling, 2008, p. 265).

2.2.3 HIV and ‘the other’

A study performed at the University of Stellenbosch, explored the role of ‘the other’ in relation to HIV (Rohleder, 2007). “In South Africa, HIV has been the subject of much politicized debate about racist projections of sexual behaviour, and issues of HIV care. This paper uses psychoanalytic theory, particularly the theory of Klein and the concept of the paranoid-schizoid position, to explore how individuals position themselves in relation to others with regard to HIV” (Rohleder, 2007, p. 401). In order to protect against threats to the self, the negative ideas attributed to the ‘self’ are projected externally onto others who then become at risk for HIV. As a result, the individual who is now HIV-positive, has to reintegrate a new notion of ‘self’, as the “individual socially becomes that ‘other’. Once again, an ‘othering’ process may take place as the HIV-positive individual struggles to incorporate these new aspects into their identity” (Rohleder, 2007, p.401). Whilst Rohleder’s (2007) research comprehensively investigates the othering process from an external perspective, the current study aims to investigate the relationship that emerges between the person and the actual virus inside them. Rohleder (2007) stated:

Joffe (1999) has used psychoanalytic theory to show how negative representations of HIV and AIDS function as a defence against threats to the self. With HIV, as with other sexually transmitted diseases, fears arise of the body being invaded by viruses; of the body being penetrated and polluted... In research conducted in Britain and South Africa, Joffe (1999) shows how AIDS is represented as a disease originating from the ‘Other’. AIDS is represented as being foreign and affecting out-groups. It is associated with

perverse and deviant practices. South Africa's AIDS campaign has used discourses which portray AIDS as resulting from deviance (p. 404).

Thus, the general distinction posits that those who are infected are the 'others' and the 'self' is he who is not infected. However, for the purpose of this research, it may be posited that the person living with HIV becomes the primary person or the 'self', and the actual virus the possibility of becoming 'the other'. In a panel discussion that focused on people's encounter with HIV/AIDS it was noted that for some people, The HI-virus was compared to a malevolent trickster type energy that used ingenious means to gain access to the host. It is an impersonal agent seeking only its own survival but if left untreated will ultimately result in the death of the host (Gosling, 2008, p. 261). Thus, the HI-virus is seen as separate from the individual, and is viewed as a negative other.

So, instead of projecting outward, the HIV may be seen as 'the other' that is the invader, and instead of projecting outward, the negativity around the virus may be projected inward. Hence, a situation may arise whereby the stigma that is usually attributed to an external object is now reversed and projected internally. "When a person becomes HIV-positive, the individual becomes the recipient of these social projections. They are forced to incorporate the split-off aspects attributed to the 'Other', internalizing the stigma attributed to them (Rohleder & Gibson, 2006, p. 28). An example of this internalization of the 'badness' can be seen in the following vignette:

Gladys is a 22-year-old African woman, living with her boyfriend. She stopped having sex with him after her diagnosis three years earlier. She said 'if I have sex with him, all the dirty things that came from me can make him very sick'. When I asked whether she felt it possible to have safe sex, using a condom, she replied, 'No, I decided not to sleep with him again, but I still love him. I'm not ready for sex now'. Gladys has incorporated the common representation of women with sexually transmitted diseases as 'dirty, diseased and undeserving' (Lawless et al., 1996), but struggles to defend against this notion of herself. She has a sense of herself as dangerous and containing 'the dirty things' that would harm others (Rohleder, 2007: 408).

In the above example, she has clearly internalized the badness and stigma of the HIV/AIDS. Thus, in some sense she and her representation of the HIV as dirty have merged, resulting in them being one and the same object.

2.2.4 Anti-Retroviral Medication

According to the World Health Organisation (WHO), antiretroviral therapy (ART) is the treatment of people living with HIV, using anti-HIV drugs. The standard treatment consists of a combination of at least three drugs that suppress the HI virus from replicating. ART has the potential to reduce mortality rates among HIV-infected people, and to improve their quality of life (WHO, 2010). “South Africa has one of the highest prevalence rates of HIV/AIDS in the world. Currently there are approximately six million persons diagnosed and living with HIV/Aids. According to the criteria that would qualify an individual for treatment with anti-retroviral (ARV) medication (T-cells less than 200), approximately two million persons currently qualify for treatment” (Gosling, 2008, p. 262). The world of antiretroviral treatment (ART) is limited in terms of research. Furthermore, there is even less research into how people with HIV/AIDS make the decision whether to take or not to take ARVs.

Recommendations of treatment guidelines are mainly based on disease severity. Physicians reported that in decision-making about ART they weighted their perception of the patient’s likelihood of adherence as heavily as disease severity. Patients’ perspectives, knowledge, and experience has for too long been an untapped resource in understanding decision-making about treatment (Kremer et al., 2006, p. 335-336).

It is interesting to note that one of the most prominent findings of the study conducted by Kremer et al. (2006) is that mind-body beliefs and spiritual beliefs were mentioned by at least half of the participants of the study as reasons to either take or not to take ARVs. For example, “people feeling that they do not need ART because they believe that the body can heal itself. As such, physicians need to be aware of and ask about the patient’s perspective on these issues” (Kremer et al., 2006, p. 344).

An American study explored the spiritual and mind body barriers that impact whether or not to take ARVs (Kremer, Ironson, & Porr, 2009). The study found that those at an advanced stage of HIV, spiritual beliefs and other mind–body beliefs were major factors in the decision not to take treatment. “Certain spiritual beliefs, such as the belief that it is not legitimate from a spiritual view to prolong life artificially, and mind–body beliefs, such as the belief that medication is not needed because the mind can heal the body, led to risky treatment choices” (Kremer, Ironson, & Porr, 2009, p. 128). Thus, it clear that the mind-body link is an influential factor when looking at the relationship that exists between the person, the HI virus, and the ARVs.

2.3 Mind/Body

2.3.1 African mind-body experience vs. Western mind-body experience

The relationship that exists between the mind and body varies greatly between cultures. In African culture there is a greater sense of community and collective ownership. “In traditional life, the individual does not and cannot exist alone except corporately. He owes his existence to other people, including those of past generations and his contemporaries. He is simply part of the whole” (Mbiti, 1969:106). Also, “feelings of self-worth in collectivist societies may depend on how well a person can respect authority and fit in with his or her important and significant relationships... This is particularly true for women in collectivist cultures” (Compton, 2005, p. 238). This notion of one’s worth emanating from community is relevant when considering the isolation resulting from the stigma attached to being HIV positive.

In contrast, most Western cultures are classed individualistic and can be described as tending “to place greater emphasis on individualism, autonomy, freedom of expression, and on each person’s internal thoughts, emotions and experiences” (Compton, 2005, p. 238).

Due to the fact that illness can be defined and expressed through culture, it is important to acknowledge cultural differences. Thus, the concept of somatization is of relevance.

“Somatization is defined as the process by which psychological distress is expressed as physical symptoms that have no known organic basis” (So, 2008, p. 167). According to So (2008), human beings share the same neuropsychological model. As a result, the way we perceive many concepts, including illness, should be similar, but this is often not the case. This is because we understand and negotiate the symptoms expressed by our bodies through lived experiences, which are shaped by our social and relational worlds. “To be sure, individuals with similar cultural backgrounds are more likely to have illness experiences and meanings that reflect a common cultural heritage. Therefore culture is a road map through which we make sense of illness” (So, 2008, p. 167-168). Eagle (2005), has explored how the traditional African worldview impacts the trauma counseling environment. She pinpoints several distinctions between a traditional African worldview and western thinking. What is most relevant to this study is the notion that in African culture the Cartesian mind-body split is negated, and the mind and body are seen as closely interrelated. Thus, for the purpose of this research it is important to

keep in mind the cultural understandings of illness and stigma that are associated with HIV/AIDS as these may influence the manner in which the HIV-positive individual relates to the virus in his/her body. For example, one area that is of relevance in terms of culture and stigma is the pressure exerted on women to reproduce. “In sub-Saharan Africa, female gender roles are influenced by the need to fulfill the roles of wife and mother. The social significance that is attributed to marriage makes it especially difficult for women to leave their husbands (risking not only social ostracism but also poverty) or to request a partner to don a condom” (Brijnath, 2007, p. 379). As a result, many women are sometimes faced with a decision that results in either contracting the HI virus leading to possible social isolation, or denying their husbands which can also lead to them facing social ostracism. Since HIV/AIDS is fraught with stigma, and since the mind and body are seen as closely connected in African culture, HIV may influence African women’s experiences of their bodies and their female roles.

2.4 Conclusion

In conclusion, this literature study aimed to provide an overview of some of the existing literature surrounding HIV. This section explored HIV according to several topics, namely: HIV and women, HIV and stigma, and HIV and the ‘other’. An outline of ARVs was also provided, and the link between the mind and body was explored in areas that could be considered relevant to this study.

Chapter 3: Theoretical Framework

3.1 Introduction

This study has explored the relationship that exists between the person living with HIV/AIDS, the ARVs, and the virus, as internal objects. Psychoanalytic theory has been consulted and more specifically, object relations theory (ORT) has been used as a lens through which to view the data. In addition to Kleinian theory, Bion's theory of containment and projective identification has been utilized to assist in understanding this dynamic.

3.2 Psychoanalytic theory

As explained by Hamilton (1988), over and above our external relationships between ourselves and others, we also have relationships that reside within us. These are not just “static images, but rather, powerful influences on how we feel about ourselves and relate to others” (Hamilton, 1988, p. 3). The first relationship exists between the infant and the parents, where the infant sees itself as undifferentiated from the parental unit. In order to protect the “self-parent relationship, we begin to attribute difficulties to things outside of it” (Hamilton, 1988, p. 3). This process of internalizing and externalizing continues as the infant develops, as the infant takes in certain parts of relationships and assimilates them into their internal world. Object relations theory is the study and exploration of these internal and external relationships and it is the outcome of these explorations that may help in understanding the mental states of both healthy and ill people.

The term ‘object’ refers to any loved or hated person, place, or fantasy and is thus used in the context of ORT as referring to anything that is invested or imbued with emotion or energy (Hamilton, 1988). Thus, an internal object refers to a mental representation, whether that is a person, place or fantasy that is relevant to the person in question. In contrast, an external object refers to an actual person, place, or thing (Hamilton, 1988).

The title of this study ‘HIV as an internal object’ is a play on words. For the purpose of this study, HIV is looked at in both a literal and figurative manner, with the actual virus as an independent or separate object within the body being explored, as well as the mental representation of HIV or how the person views the object based on previous relationships. The

second and more figurative exploration has been informed and supported by Melanie Klein's theory of object relations, as well as Bion's theory of projective identification.

3.2.1 Kleinian Theory

While "Freud first elaborated how identification processes influence the form of adult association... this was elucidated further by Klein's concept of projective identification" (Nuttall, 2000, p. 213). Hence, it is of relevance to this research to provide background to Klein's concept of object relations, as this construct will help to illustrate how internal objects come to be negotiated. According to Rohleder (2007):

Klein (1959) talks of defensive positions which originate in infancy. In the paranoid schizoid position the infant splits its experience of the 'good', nurturing mother that is loved, as separate to the 'bad', frustrating mother that is hated. The infant's early interaction with the primary object consists of both gratifying moments and frustrating moments. When the infant's needs are fulfilled, the mother is experienced as nurturing and loving. When the infant's needs are not fulfilled, the mother is experienced as persecutory. In order to maintain the good experience of the nurturing mother, the infant separates the 'good' mother from the 'bad'. Through the unconscious defence mechanism of splitting, the good experiences are taken into the self, and bad experiences are projected outwards (p. 405).

Therefore, according to Kleinian theory, from infancy the first object a person encounters is the mother's breast, which is viewed as both good and bad. These positive and negative perceptions are either introjected or projected, and assist in the formation of the person's internal world. Thus, early object formation impacts upon the mental representations that a person draws upon later in life. "In early infancy anxieties characteristic of psychosis arise which drive the ego to develop specific defence-mechanisms" (Klein, 1946, p. 1). Bronstein (2001) defines this anxiety as "the fear of annihilation of life, which arises from death instinct within" (p. 113). This anxiety is thought to originate from the pain, discomfort, and loss of the intra-uterine state that are felt as an attack by the infant (Klein, 1952). Klein (1952) argues that the ego is present from the beginning of the infant's life; however, the ego has not yet reached full development and is therefore under the control of the unconscious. The ego's first activities are to defend against any anxiety experienced as persecutory anxiety via the use of defences. It is this anxiety and fear for the loss of one's internal good objects that the ego has identified with, that initiate the employment of primitive defence mechanisms: splitting, denial, projection, introjections, projective identification, idealisation and disparagement (Bronstein, 2001).

During the second quarter of the infant's first year the intellectual and emotional development changes the way the infant relates to the world. The infant no longer relates to its objects as part objects, as in the good breast and the bad breast, but now is able to relate to the object as a whole (Klein, 1952). In other words, the infant is now able to view the mother as a whole and no longer as a part object. In this position there is a change in the nature of the defences that are present. Split feelings of 'love' and 'hate' are now able to come together. This more reconciled position is known as the depressive position. Ambivalence is now felt towards the complete object. This leads to depressive anxiety and guilt and a need to make reparation (Klein, 1952).

In healthy development, normal splitting helps to organize chaotic experiences and provides primitive ego structuring and it is at this stage that the alternation between persecutory and idealized states are seen. This allows time for ego strengthening to occur, which then, in turn, allows for greater integration and a greater tolerance of ambivalence (Segal, 1957). The sense of omnipotence that characterises the paranoid-schizoid position fades, and it is replaced by the recognition of one's dependence on another human being, who is now seen as a separate person. "The egocentric, narcissistic attitude, in which the infant conceives of objects in relation to himself, as being good or persecutory to himself, gives way to the relationship to another person seen as having her own feelings, problems, and relations to other people as well as oneself" (Young, 2000). Thus, "the infants shift from an ego-centred to an object-centred state, which is held to be the crux of the depressive position" (Likierman, 2001, p. 115).

Melanie Klein's conception of projective identification refers to a process by which the infant, in phantasy, projects parts of 'the self' into objects. The concept of 'self' is difficult to define and refers mainly to the private internal mental representations that pertain to one's own person (Hamilton, 1988, p. 12). Broadly, in terms of ORT, the 'self' refers to the subject as in the individual, and the object is something that is either loved or hated. This object can also be either internal, a mental representation, or external, a real person, place, or thing (Hamilton, 1988). The above mentioned concepts will be elaborated upon further in the study. These objects are usually the mother or caregiver. For example, the baby learns to differentiate that its mother is distinct from strangers, thus allowing the development of a solid awareness that the self is in fact distinct from mother (Hamilton, 1988).

In relation to HIV, previous research has found splitting to be a common defense mechanism that is utilized. The first occurs between the 'self' and the 'other'. For example, for the individual who is uninfected with HIV, the 'self' is seen as 'good' and the 'other', the person living with HIV is 'bad' and is therefore rejected. Hence, the 'self' remains the pure primary self that does not have HIV, and in order to defend this pure and uninfected 'self' the 'other' becomes those that are infected with the virus (Rohleder, 2007). Other research, proposes a slightly different concept whereby the 'self' is the one who is infected with the virus, who is responsible for knowing their status and thereby good, and the 'other' refers to those who probably have virus but are unaware of their status and are therefore bad (Rohleder, 2007). Thus, a defense mechanism is employed that helps to preserve the 'self'. In the latter concept, even when the 'self' is now 'impure' due to being infected with the HI virus, an othering process still occurs whereby the 'others' are seen as bad due to their ignorance. What this research has entertained and explored is the notion of the primary self being the 'self' and the 'other', being the HI virus that is living inside the primary self's body. Thus, the internal relationship has been explored according to what occurs between these two entities. To elaborate, the situation now exists where the 'self' is preserved as good, but the internal body is now tainted by the HIV: the negative internal object.

Another important aspect of object relations theory that needs to be considered is the influence of primary relationships on later relationships. According to Klein, "Object relations refer to the collection of internal representations within each individual. These representations of important people and relationships shape how one feels when in relationships, the outcomes one expects from relating to others, and presumably how one interacts with others" (McKay, 1991, p. 641). In light of this concept, is it then possible that the relationship the participants have formed with the HI Virus inside their bodies may be affected by the participants' previous relationships? For example, "people with harsh, malevolent, or generally negative internal representations of relationships carry around the experience of rejection, loss, or disappointment. Although they may not be experiencing difficulty or pain related to a current relationship, they may still experience considerable stress and dysphoria because of their conscious and unconscious beliefs about how they will be treated by others [or the HI virus]" (McKay, 1991, p. 641). Thus, an

individual's previous experiences may affect the way they view their current experiences. These experiences are not restricted to interpersonal relationships, but may extend to socio-cultural experiences. This raises interesting questions regarding the link between Object Relations Theory and PNI, for example, a person's previous experiences which become internalized as internal objects may influence the manner in which that person relates or views their illness.

3.2.2 Bionian Theory

In addition to Kleinian theory, Bion's theory of containment and projective identification can also be used to understand the aforementioned relationships. What is of particular interest is the idea of being able to think about the virus. According to Bion, the ability to think one's own thoughts is crucially important, as is the ability to think about one's own experience, to think about others experiences, and to rise up against one's 'personal internal resistance to acknowledge painful realities' (Ivey, 2009, p. 113). In object relations, what is thought to make up the link between objects is emotion or feeling, however, for Bion (1962) another link between objects is thinking. Bion's major concern was the application of thought to emotional experience, and he states that an emotional experience cannot be conceived of in isolation of a relationship (Symmington & Symmington, 1996). Bion's concept of 'thinking' is not referring to the frequently used term associated with cognitive processes of the brain, but rather to the process by which an individual attempts to know himself or another. According to O'Shaughnessy (1981): "His concern with thinking is as a human link, the endeavour to understand, comprehend the reality of, get insight into the nature of, etc., oneself or another. Thinking is an emotional experience of trying to know oneself or someone else" (p. 81). Klein laid a crucial foundation for this view by differentiating between "intrusive curiosity, stimulated by a voyeuristic need to 'know' in order to master and control, and a more enlightened desire to understand; something more akin to a thirst for knowledge, in the interest of growth rather than of mastery" (Waddell, 1998, p.102). It is this interest in growth that differentiates the emotional knowing characteristic of a K link from the desire to fill the intellectual storehouses of the mind with knowledge as a commodity, enabling oneself to avoid personal meaning and growth (Waddell, 1998). In contrast to K, Bion allocated the symbol -K, which he conceived of as a resolve not to know. According to Bion (1962) "...an emotional experience that is felt to be too painful may initiate an attempt either to evade or modify the pain according to the capacity of the personality to tolerate frustration" (p. 48). According to Bion (1962) when there is "a need to be rid of emotional

complications, of awareness of life and of a relationship with live objects” (p. 11), knowledge of painful internal and external reality is evaded. Thus in reference to this study, Bion’s theory is helpful in understanding the way the women are able or unable to think about the HIV in their bodies.

Bion proposed that the capacity to think evolves in the interpersonal context of the mother-infant relationship. The container-contained model explains how infants acquire the internal space in which their thoughts are ‘housed’. Containment, Bion’s term for the process by which our unbearable feelings are made bearable, helps us find ways of confronting painful realities through active engagement with our own experience (Waddell, 1998). The infant experiences his thoughts and feelings as beta elements, which are the frightening, raw, and essentially meaningless experiences. These are projected into the mother who accepts, tolerates them, and digests them for the infant giving them back in a more manageable form. This digested feeling, or alpha element, is reintrojected by the infant thus making the meaningless meaningful and tolerable (Bion, 1993). The infant can now use the experience in thoughts, dreams or other symbolic process which make up mental life (Ivey, 2009). The beta elements come to have meaning and they are, in this way, able to be endured. If this happens often enough for the infant, the function is internalized and the infant can perform this function for himself, internally. This process is called containing (Bion, 1993). But when containment is out of reach, evasion of these painful realities abounds, with negative consequences for both mental growth and the capacity for thought. In relation to HIV, for some people living with the HI virus it may be possible that they are unable to think about the virus in their bodies, thus inhibiting their ability to accept and engage with the reality that surrounds it. This could in some way prevent the process of acceptance of their illness.

3.2.3 Projection

In addition to the HIV- positive individuals’ own projections, they often also have to deal with society’s projections around HIV/AIDS. While this study has explored the participants’ mental representations of the HI virus in their bodies, it has been kept in mind that it is likely that society’s views around HIV also influence the relationship that HIV-positive people have with the virus within their bodies, and the feelings and perceptions of HIV-positive people. As mentioned previously in the Rohleder and Gibson (2006) study, it is most likely that participants

will draw on the more negative societal representations of the HI virus. Society's perceptions around HIV were further investigated by Squire as cited in Rohleder (2007):

When a person becomes HIV positive, they are forced to incorporate these split-off aspects of themselves attributed to the 'other', as they themselves become the recipients of the negative social representations of HIV. When first diagnosed, individuals may initially draw on the more negative representations of HIV. It was these negative discourses that individuals tended to invest in when positioning themselves as outside of those at risk. Individuals often experience feelings of shame, fear and a sense of being dirty when diagnosed HIV positive (Squire, 1997). The self becomes threatened as the individual has to incorporate the 'bad' identity. Under such threat, primitive defensive positions may be activated (p. 407).

As Rohleder and Gibson (2006) argue, the recipients of these projections are not just passive receivers of this stigmatization, but rather that recipients may challenge and fend off some of these projections. Hence, this study has explored the complex relationship between the participants, the ARVS, and the HIV in their bodies. It has also considered the influences of previous relationships and cultural stigma on these relationships. Looking at the way in which the virus itself is perceived within the person's body may shed light on this complex relationship.

The idea of viewing HIV as an internal object is both interesting and complex. The internal world of someone living with HIV is technically under siege and at the mercy of the HI virus. "The central function of the immune system is to protect the host from invading pathogens and preserve the integrity of the internal body. The internal world is known immunologically as 'self' and potential infectious agents that could be recognised by the immune system from the external world are known as 'non-self'. The central paradigm of immunity is recognition of 'non-self' and preservation of 'self' (Gray, 2005:120). This serves to support this study's position of viewing the person as 'self' and the HI virus as the 'other'. However, it may be of import to note here that a particular feature of the HI virus is that it invades human cells, joins with the DNA in these cells and then replicates, changing the DNA as it progresses. This brings into question the 'separateness' of the HI virus from the body of the host and this study has explored how this concept of separateness is thought about and experienced by the participants in the study.

3.3 Conclusion

In conclusion, this chapter provided an overview of the theoretical framework that is utilized in this study. As mentioned previously, this study explored the relationship that exists between the

person living with HIV/AIDS, the ARVs, and the virus, as internal objects. Through the use of in-depth interviews, several themes emerged and psychoanalytic theory was consulted and more specifically, object relations theory (ORT) was used as a lens through which to view the data. In addition to Kleinian theory, Bion's theory of containment and projective identification was utilized to assist in understanding these dynamics.

Chapter 4: Methodology

4.1 Introduction

This chapter provides a detailed description of the methods used in this study. It provides an overview of the research method, exploring the paradigm within which this research falls. How participants were chosen for this study is detailed, as well as the method of data collection and data analysis. Furthermore, the particular method chosen is motivated for and elaborated upon.

4.2 Research questions

1. What are the participants' thoughts, feelings, and perceptions of the virus within their bodies?
2. What are the participants' thoughts, feelings, and perceptions of the ARVs within their bodies?
3. What are the participants' thoughts, feelings, and perceptions of the relationship between themselves, the HI virus, and the ARVs?

4.3 Research methods/approach

This study has used qualitative research methods. "Qualitative research aims to address questions concerned with developing an understanding of the meaning and experience dimensions of humans' lives and social worlds" (Fossey, Harvey, McDermott & Davidson: 2002, p. 717). Due to the fact that this research aimed to explore the participants' subjective experience of the relationship that exists between themselves, the HI virus, and ARVs, a qualitative design was most appropriate. In addition, qualitative research is suitable for this research as the information gained from the transcribed interviews yielded rich data that allowed for in-depth analysis and interpretation of the participants' perceptions. This research has continuously aimed to authentically convey the participants' perspectives and subjective experience, as understood by them. Psychoanalytic theory was then applied to these understandings.

This study fits the criteria for both an inductive and deductive paradigm. As a result of the qualitative research design, this research falls under the interpretive paradigm. This paradigm places "emphasis on seeking understanding of the meanings of human actions and experiences, and on generating accounts of their meaning from the viewpoints of those involved" (Fossey et al., 2002, p. 718-720). Furthermore, since it is the participants' own subjective experience that is

being valued most highly, it is the interpretive paradigm that this research falls under. It is an inductive approach, as it focuses on building themes in an upward sense. However, after collation, thematic analysis and presentation of the data, these themes have been viewed and interpreted through a psychoanalytic lens and discussed in this manner. Hence it is at the same time deductive. Deductive or theoretical thematic analysis tends to be driven by the researcher's theoretical stance (Braun & Clarke, 2006). Hence, for this study, the researcher has viewed the data from a psychoanalytic stance.

4.4 Participants

The participants for this study were selected using convenience and purposive sampling. Specifically, the sample was comprised of 6 HIV positive women who were residents at a women's shelter. The number of participants was dependent upon the number of interviews it took to establish a pattern. Thus, when new themes ceased to emerge, the interview process was brought to an end. It must be noted that the participants from the women's shelter are a group of socially vulnerable or marginalised black women. Therefore they are not women who are self-sustaining or women that are functioning within their families and communities. Hence, they cannot be considered to be representative of black¹ HIV positive women in general.

In recruiting the participants, a letter regarding the details of the research was submitted to the Director of the women's shelter and permission was granted to conduct the research at her facility (See appendix 9.5). Thus, once ethics clearance was obtained from the University of the Witwatersrand (WITS), the researcher was able to invite potential participants to be interviewed.

At the time of the study, the participants were all between the ages of 18 and 65 years old, and had been diagnosed with HIV for at least a year. In addition, the participants were all currently taking ARV medication. It was ensured that the participants were healthy enough to be interviewed, and the fact that the participants have been infected with the HI Virus for at least one year, allowed for sufficient time to have passed so as to allow a relationship to develop

¹ *Although the use of the word black may imply the use of racial categories associated with Apartheid, the use of the word here is used merely for clarity's sake.

between the participant and the virus. The aspect of language was not a problem as the women at the shelter were all sufficiently proficient in English.

There were few inclusion and exclusion criteria for this study, with the women being HIV positive for at least a year, and currently taking ARVs being the only inclusion criteria. In one instance, it was necessary for the researcher's judgement to be asserted and one interview was stopped midway and not included in the study, as the woman appeared to be ill and in pain and the researcher felt it unethical to continue.

4.5 Data collection

Prior to the interview process, the participants from the shelter were briefed by the director. She addressed the women residents at the facility and conveyed the main aim of the research. Once the women had been briefed and if they chose to participate, they were able to either directly contact the researcher or they could place their names and contact details in a designated box. The researcher then contacted these women to arrange a time to conduct the interview. This ensured that participation in the study was kept confidential. Although the director may have been viewed as an authority figure that may have the potential to coerce participations, this was discussed with the director and the voluntary nature of the study was emphasised. A prerequisite to living at the shelter is for the women to provide proof that they are HIV-positive. Thus, the HIV status of the women who live at shelter was already disclosed.

Once the researcher had made contact with willing participants, suitable times were arranged to conduct interviews with the participants. Due to transport logistics, and in order for the researcher to engage with the participants in their setting and understand their social environment, the interviews were conducted at the participants' convenience at the shelter in a private room. Various methods of consent were obtained. A consent form regarding the interview was given to the participants, as well as a consent form granting the interviewer permission to record the interview. For more detailed information regarding these consent forms, please see the Ethical Consideration section.

This research utilised semi structured interviews in order to gather data (See Appendix 9.1), as they “facilitate more focused exploration of a specific topic, using an interview guide” (Fossey et

al., 2002, p. 727). This style of interview was suitable for this research, as it enabled the interview to be “focused, yet flexible and conversational” (Fossey et al., 2002, p. 727), which put the participants more at ease when discussing a sensitive topic of this nature. The credibility of the data was also established during interviews, as the participants’ intended meanings was checked and clarified (Stiles, 1993).

The interviews utilised in this study had a tripartite structure (Hollway & Jefferson, 1997), focussing on (1) the relationship that exists between the participant and the virus and how they view the HI Virus, (2) the relationship that exists between the participant and the ARV’s and how they view the ARV’s in their body, and (3) how the participant views the relationship that exists between themselves, the HI Virus, and the ARV’s within their body. In addition, the participants were asked to complete one drawing. First, participants were asked to draw the HI virus in the bodies, which was followed by asking the participant to insert the ARVs into the same picture (for exact instructions that were given please see Appendix 9.1). The aim of this exercise was to elicit more detailed information regarding the participant’s mental representations and perceptions of both the HI Virus, as well as the ARVs. In addition, the drawings were also used as a point of departure during the interviews, and allowed the participant to speak more freely about their perceptions of the virus and the ARVs. In the event that the participant did not want to draw, they were encouraged to do so but were not forced. It was stated that the drawing need not be advanced or elaborate, but merely whatever they felt they wanted to draw. If they still did not want to draw, they were still included in the study as the researcher was able to infer certain attitudes towards the HIV from the refusal to engage in a drawing.

The use of projective techniques for this study allowed for information to be elicited about the participant’s direct or indirect understanding of the HIV/AIDS in their bodies, as well as the ARVs. An advantage of using projective drawings is that they require minimal language skills, few materials are needed, and both the conscious and unconscious may be accessed (Cohen & Snerdlik, 2001). Furthermore, the benefit of drawings as a method of data collection was discussed by Guillemin (2004), who used drawings in conjunction with interviews to explore Australian women’s perceptions of heart disease and menopause. Scott (2009) claimed that the

drawings used in her study to investigate HIV “produced unique insights, enriching the data collected while also adding credibility to themes identified using other methods” (P. 464). In addition, there is a relative scarcity of studies that use drawings with adult participants (Guillemin, 2004).

A study performed by Paola Luzzatto (1987) also used projective drawings in order to explore the internal worlds of drug-abusers and their visual representations of their internal world, which is similar to what this study explored. In Luzzatto’s pilot study, the drug abusers were required to use an art therapy technique called the ‘self-image’, and their projective pictures of self-object relations were analysed using the object relations theory (Luzzatto, 1987, p. 22). Four types of ‘self image’ emerged from the study: the vulnerable self, the objectless self, the divided self, and the integrated self. For the purpose of this study, a variation of the same art therapy technique was used in that the participants were asked the ‘draw the virus in their bodies’. Whilst the drawings allowed for insight into the internal worlds of the participants, the drawings were also used as a point of departure. As mentioned by Backett and Alexander (1991), the researcher may use the drawings essentially as an ice-breaker to open a semi-structured qualitative interview.

“Information gathered during the data collection needs to be recorded in a manner that enables the researcher to analyse the data, but also allows him or her to describe subjective meaning and social context from the data” (Fossey et al., 2002, p. 728). For this reason, and since the actual words of the participants were needed to convey and interpret the subjective relationship that is formed between the participant, the HI Virus, and the ARV’s, both note-taking by the researcher and full verbatim transcriptions of the interviews was conducted. These field notes “describe not only the researcher’s experiences and observations, such as those made while engaged in participant observation, but also his or her reflections and interpretations” (Fossey et al., 2002, p. 728).

The interview schedule dealt with approximately eight areas (See section 9.1 Interview questions). These open ended questions had been carefully structured and discussed with the supervisor. The themes that were addressed have been supported and motivated in Section 9.1.

4.6 Data analysis

“Qualitative analysis is a process of reviewing, synthesising and interpreting data to describe and explain the phenomena or social worlds being studied” (Fossey et al., 2002, p. 728). Once the interviews were completed, they were transcribed verbatim, to form the raw data that was subjected to analysis. Both recordings and transcriptions have been stored as password secure mp3 and word doc files, respectively, ensuring the confidentiality of the participants.

Once transcribed, the data was analysed using thematic content analysis (TCA). This form of qualitative analysis is a discovery-focused technique which aims to establish patterns and connections among elements of the data, thus eliciting themes (Fossey et al., 2002). Since the research examined the data and elicited themes that reflect the participants’ subjective perceptions of the relationship that exists between themselves and the HI Virus, thematic analysis was most suited. “Thematic analysis typically involves a constant comparative method, meaning a progressive process of classifying, comparing, grouping, and refining groupings of text segments to create and then clarify the definition of categories, or themes, within the data” (Fossey et al., 2002, p. 728-729). Thus, it is an inductive approach, as it focuses on building themes in an upward sense. However, these themes were viewed and interpreted through a psychoanalytic lens, so the study is at the same time deductive.

This process entailed six structured steps as outlined by Braun and Clarke (2006). However, this was not a linear process, but rather a recursive process that required the researcher vacillating from one step to another (Braun & Clarke, 2006). Firstly, the researcher needed to familiarise herself with the data. This involved transcribing the data, repetitive reading of the data, and documenting initial thoughts surrounding the data. The second step involved generating the initial codes. This required the researcher to systematically collate the data across the entire data set. Consequently, the third step involved searching for themes, whilst the fourth step involved reviewing the themes that had emerged with the researcher’s supervisor, in order to ensure the stability of the data. Thus, a thematic map emerged after the first four steps. The fifth step, the finding and naming of themes, required the researcher to generate clear definitions and specifics for each theme. Finally, the sixth step involved the discussion of these themes in relation to relevant concepts from object relations theory, resulting in the production of a report (Braun &

Clarke, 2006). For each of these steps, the researcher consulted the supervisor of this study, so as to ensure that methodological guidelines were adhered to.

In reference to the drawings, the researcher analysed the participant's depictions of the HIV and the ARVs by looking for recurring themes. Thus, the drawings themselves underwent a thematic content analysis. The themes were then viewed through a psychoanalytic lens, in much the same way that the narratives were viewed. The analysis of the drawings was guided by a technique developed by Guillemin (2004), who was influenced by Rose's (2001) critical visual methodology framework. This technique of analysis involved looking at questions that address certain aspects around "the production of the image, the image itself, and the site where it is seen by various audiences" (Guillemin, 2004, p. 284). However, Guillemin (2004) has modified this approach to include the participant, the researcher, and the image itself.

In order to reflect the perspectives of the participants in a responsible and accurate manner, the report has made use of quotations taken from the verbatim transcriptions, juxtaposed with the researcher's descriptions and interpretations. This will assist "the reader to evaluate the authenticity of the researcher's claims about the data" (Fossey et al., 2002, p. 730).

4.7 Ethical considerations

Since this study has examined vulnerable participants, those living with HIV, ethical considerations needed to be closely addressed. Several procedures were carried out in order to prevent any harm being brought to the participants. Firstly, informed consent was gained from the Director of the women's shelter (See appendix 9.5). Also, ethical clearance was sought and granted from the Wits Ethics Committee (See appendix 9.6). There were also several forms presented to the participants: a consent form for the interview, a consent form to allow for the session to be recorded, as well as an information sheet (See appendix 9.2, 9.3, & 9.4).

As mentioned above, the participants from the women's shelter were briefed by the director. She addressed the women at the facility, conveyed the main aim of the research and invited the women to participate. Once the women were briefed, they were able to place their names and contact details in a box if they so choose to participate. The researcher then contacted them to arrange a convenient time to conduct the interview. Due to the fact that the director already knew

the HIV status of the women (women have to provide proof of their HIV status in order to live at the shelter), it was decided by the researcher that having the director invite the participants would be less intrusive than having the researcher approach the women already knowing their status. However, since the women were placing their names in a box, their choice to participate in the research remained confidential.

The information sheet stated, in an accessible manner, the main aim of the research, as well the data gathering procedure which was explained so as to prepare the participant for where the interview will take place and for how long the process will last. Several statements were made to convey that confidentiality would be adhered to and that the participants would be able to withdraw at any time during the study if they so wished without any disadvantage to themselves. The information sheet also clarified that the participant may choose not to answer any questions during the interview and that the data collected would be kept in a safe place for two years should publications arise from this study or for six years should no publications arise, and thereafter destroyed. The information sheet provided the researcher's contact details and position, as well as the supervisor's details.

In order to ensure that the ethics of the study were preserved all questions and themes that were addressed in the interview, were piloted, as well as carefully considered during supervision. Finally, in order to ensure that the study presented as minimal risk as possible, a debrief session following the interview was made available, and recommendations for additional counseling were passed on to the participants if deemed necessary. For example, the details for the Centre for the Study of Violence and Reconciliation (CSVR) (011 403 5102/3), Emthonjeni Community Clinic (011 717 4513), as well as telephonic services were provided (Lifeline = 0861 322 322). These are all free counseling services.

In addition, upon completion of the study, the participants may request a summary of the report that will be sent to the women's shelter.

4.8 Conclusion

In conclusion, this chapter supplied a detailed and comprehensive discussion of the research methods utilized for this study. The research design, participants, method data collection and

method of analysis, have all been addressed, and for each step and chosen method, a clear motivation was provided.

Chapter 5: Results

5.1 Introduction

In this chapter, the results of the study are presented along with some of the drawings made by the participants during the interviews. The results are organised into eight major themes, yet for many of the themes a continuum seems to exist, with each pole representing an extreme. For example, for the major theme of thinking, two poles exist on what could be considered a continuum, with being unable to think resting on one extreme, and being able to think on the other extreme. The results are presented in as close to as raw a manner as possible and objectivity was attempted throughout the analysis process. However, due to the nature of thematic content analysis, the researcher's subjectivity was held in mind.

The researcher's reflexive response to the data and the participants fluctuated throughout the research process, and is notable due to the subjective nature of qualitative research. When conducting the interviews, the researcher at times felt deeply touched by the women's stories, and this was often accompanied by a wanting to rescue or intervene. When listening to the hardships and discrimination the women had been exposed to, a certain degree of anger was also evoked. This anger was at times directed towards the women's families and spouses, who seemed to have abandoned the women in what was felt to be a time of need. As a possible response to this anger, there was sometimes a pull to make the women appear stronger and more cohered; that they had triumphed and overcome their difficulties. However, these emotions were acknowledged by the researcher and an attempt was made to separate them from the analysis process as much as possible, so as to allow for a broader and perhaps more realistic look at how the women perceived the HIV in their bodies.

5.2 "Right now I can' think": Thinking vs. Unable to think

The theme of being able to think about the HI virus was prominent amongst the women in the study. For some of the women it was clear that it was difficult to think about the HIV, with some of them claiming that they not previously thought about the HIV inside their bodies before. During the interviews, it became evident that some of the women struggled to engage with the concept of thinking about the HIV inside their bodies. Mafuwa, when asked to draw the HIV in

her body, was initially unable to engage with this exercise and unable to think about the HIV: “(thinks for a while) I have no idea what I’m going to draw (laughs) can I also write words?”

During the interviews it seemed that several of the women had previously not thought about the virus inside their bodies, thus making this exercise challenging. Occasionally the women would elaborate spontaneously when asked to speak about their drawing, but the majority of the time they would become silent, waiting for the next prompt. However, with all of the women in this study, as rapport developed and as the interview wore on, so did they become more able to elaborate independently. When asked if this was a new idea for her, Nomvula claimed that “...it just came to me quickly right now, sitting here”.

In the stories that some of the women shared, it became clear that HIV has been hard to think about all along. For Siphwiwe, the process of diagnosis was compounded by her confusion around not knowing. She describes initially being unable to engage with her experience as a result of a lack of knowledge, which seemed to enhance her sense of helplessness.

It was very scary. He was 3 years old, but he looked like he was one years. He couldn't walk. He couldn't run. He couldn't do nothing, he was so tiny. I mean I know I'm tiny, but he was so so tiny. And he had diarrhoea and stuff and I just didn't know what was wrong. So I went to the clinic and they told me he was HIV positive. And I said, you must be lying, test me now.

Being unable to think about HIV also became apparent when going to get tested, and perhaps worked as an inhibiting factor, preventing the women from getting tested and thus defending them against the prospect of being HIV positive.

...And he suggested, you know what lets go get tested for HIV. I was so surprised. Why do you think about this? And just said no lets go get tested, because I have got some of things I also don't understand in my body too. So we went there and I was not expecting a positive result at all. When we were there, we tested, and then they said are you ready? and I was so confident and then they said you are HIV positive. Oh my god. I didn't cry. I didn't do anything. I was just so shocked. But he said no lets just go home. I wanted to grieve. I wanted to take this thing out of me. Then I cried really. I cried a lot.

In the above extract, Linda's initial thought about being HIV positive seemed muddled; affected by her reaction of grief, shock, and denial. However, being unable to think about the virus seems to change from diagnosis onward. In the following extract, Nomvula demonstrates how in the

beginning she was unable to think about the virus, but as time went on she developed a capacity to think about it:

...In the beginning, I didn't believe I was HIV positive, and in the same time I was surprised how I am positive because I usually test and I am usually negative. So, I went for testing and I was quite confident I was going to be negative, so when I was positive I didn't believe it. But as time goes on, I realized it is true and I must accept it, so that I can live because it is going to kill me if I reject it. Because it is really looking for those who doesn't accept it.

During the interviews some of the women, instead of thinking about the HIV on a personal level and inside their bodies, were only able to intellectualise about the HIV. Thus, they were able to think about it from an outside or external perspective, but were unable to grapple with it on a personal level. Mafuwa stated: "Right now I can't think. I haven't thought before of what it looks like in my body. But I do remember seeing a picture of it a while ago when someone was showing me what it looked like. But now I can't remember". Mafuwa appeared to resort to her existing knowledge on an intellectual level when asked to think about the HIV in her body. She was unable to think about the HIV without referring to an external point of reference. She seemed to be fairly defended against grappling with what it is and what it means for her. This way of thinking about the HIV was common.

For some of the women, the notion of being able to think about the HIV seemed dependant upon the knowledge they possessed about the virus. In some sense, being educated about the virus allowed for them think about it whilst on the other hand it may also have acted as a defence mechanism, distancing them from having to engage with it on a personal level.

The above concept is clearly displayed in Mafuwa, who when asked how her views about the virus have changed, reported that the knowledge she had gained allowed for her to be able to think about the HIV and gain some control over her life:

Yes I think it has definitely changed. When I first found out I was devastated. I didn't believe I would be alive for even a week. I thought I am dead already. But as time goes on, the knowledge I got from the hospitals, I learnt I still have life ahead of me. This is not the end of it. I can still make it even with this HIV.

Thandi agreed with Mafuwa on this matter, claiming that: "Well now I think knowledge is power. Because I think if you the medication that's fine, but if you have no knowledge of it, it is

like...it is like...not knowing anything”.

Several of the women claimed that the possession of knowledge about HIV allowed for themselves and their families to be able to engage with the virus and the stigma that surrounds it. However, the converse of this seemed to also be true, whereby a lack of knowledge seemed to inhibit the person and their family’s ability to think about the HIV. When asked about her experience of the stigma surrounding HIV, Mafuwa claimed that:

... before they got knowledge about HIV because like my mom the way she was taking it, it was like she was thinking you can get it, it is flying in the air, or you can get it from touching somebody. Because I remember with my last born, I gave birth there in Mpumalanga. Then there was a time when my brother came to visit to see my little daughter. And someone wanted to kiss the little daughter on the forehead and my mother pushed them away. So you could see from her reaction that she was sending the message that ‘don’t kiss him or you will get AIDS’.

Another one of the women, Linda, claimed that knowledge about the virus also affected the way her family dealt with her HIV positive child:

They need education because that’s what makes people not able to accept it, and also how do I say for example, if I am HIV positive I might not be encouraged to do so many things. They just let me down. You are going to die... ya they don’t understand really, but I understand that an HIV positive can understand better than a person who is negative. As for me, I think HIV is better than some of the diseases out there. You know cancer can kill. Even high blood can kill...in a sense. My mother is that person; I don’t think she knows much about HIV. She knows that thing that HIV can kill. I think the thing is that they need to be counselled. She might jump to the wrong conclusions.

A lack of knowledge was also associated in the women’s minds with fear, stigma, and discrimination. Nomvula spoke of how a lack of knowledge can result in a person being unable to cope with their HIV positive status,: “ I think at the location if I just scream and tell people, tell everyone that I am HIV positive, some they don’t know about this HIV thing. So if I scream and tell them at the end of the day they will pull me down. They will bring that stress back; they will bring those fears back. They will give me their fears”.

When exploring the women’s perceptions of HIV, a strong theme that emerged was that of the power of the mind, the power of being able to think about the HIV, affecting the course of the virus itself. Linda spoke of this idea: “There are so many things that can make you angry. I think the mind is supposed to control you and you can’t control your mind. Even here you can get

stressed, and if you can't control it. The mind and body needs to be connected so you can relieve stress". Nomvula agreed to some extent with the above idea, claiming that:

I think HIV, if in your mind you are always seeing it, always saying 'I am HIV positive, I am gonna die', the more the HIV positive becomes strong in your body, because stress helps HIV to move. You use you mind to be stressed. And if you are sad you also support HIV. 'Coz if you are stress free then HIV is powerless. If you are always happy and accepting everything you don't let HIV get stressed.

Thus, for some women, being able to think about the HIV allowed for them to gain some control over the virus, thus making them more powerful. In light of what is mentioned above, for Thandi, the mind was also a prime target for the HIV:

Yeah I mean that it affects your brain. It affects your brain so much and you can't function without your brain. And it all then goes down to the body. *Z is adding into her drawing as she speaks.* You can't eat. You can't function. Then it goes down to the legs... on the outside it shows you are getting thinner. You don't have an appetite. And the brain now, it starts to tell you stories. Because the major thing, if it's HIV, is the brain...And you know when we are created, the brain if the brain is dead, then you are as good as dead. So the brain it controls you. Less so than the heart.

For Thandi, the mind is a powerful place and the HIV could affect that the most, thus in some sense targeting the most powerful weapon against it. Following on, Nomvula spoke of how talking about HIV, knowing one's status, and thinking about the virus also makes one more powerful and less helpless:

...When I can from the clinic I didn't announce to everyone at all, I told my husband and my other friend first. And even my husband he didn't talk, he doesn't want to discuss about it. He's ignorant. He doesn't even know his status anyway. He doesn't even know his CD4 count. Yeah but when I talk about it I feel strong and more confident.

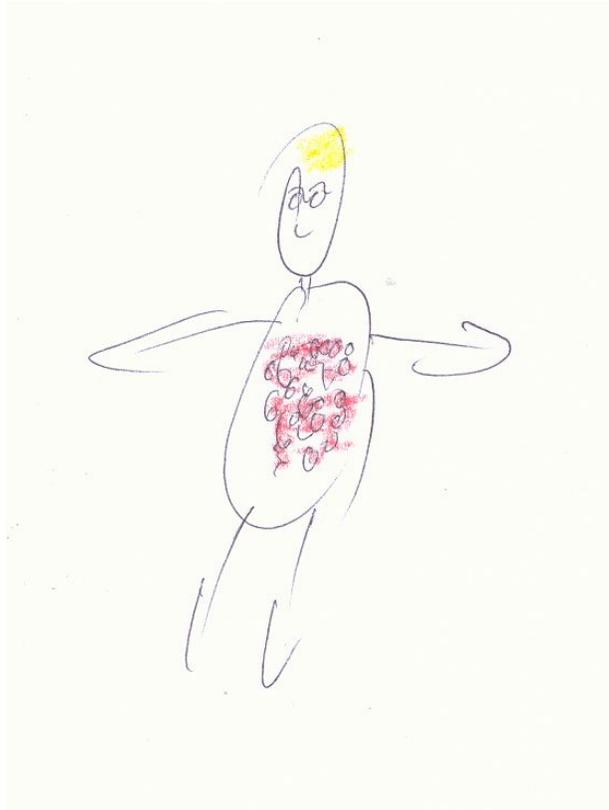
Overall, the women who were interviewed depicted the capacity to think about the HIV as being inhibited by factors such as denial, sometimes in the hope of defending the person living with HIV from engaging with the reality of it. There seems to be a discrepancy between factual knowledge and emotional knowledge. For some the women, it seemed to be easier to engage with factual knowledge about the virus, rather than engage with the emotions that diagnosis evokes. It seemed that the ability to engage with thought around the HIV and to be able to think about it, improves areas such as stigma and isolation, and allows for the person to gain control and power over their lives.

5.3 “It’s like a criminal”: HIV as danger

For all of the women, the HI virus was connoted with concepts that represent danger, with this idea ranging from an act of attack, to an act of theft. From the drawings, the majority of the woman chose to use the colour red to represent HIV, with red connoting danger. When asked to describe how she viewed HIV in the body, Thandi felt that, “...Red is danger, and danger is in the brain...from the word go it is ‘horror’ ‘death’ ‘isolation’ ‘depression’, but the main thing is ‘death’”. Linda still felt HIV to be connoted with danger; however she felt that the HIV was best associated with the colour black:

...you know, in me I can say, anything that attacks I can put a black colour. It’s not good. So black to me is just not a good colour when talking about white things or red things, black can’t make anything good. Anyway talking of the body, I know the blood is red. If anything gets into the blood, the blood can change the colour maybe to a blackish or let me say dark grey. It might be like that. That’s why I took this colour. Maybe my blood might not be flowing reddish. It is contaminated with this colour (*pointing to black*). So am I thinking maybe this is HIV and it is flowing in this red blood making it dark and not red anymore.

Mafuwa felt that HIV was something that, “...makes me feel helpless. I think I can also describe it as a thief, because it stole my everything...my happiness. It’s like a criminal... it would be someone who ruins people’s lives. I think it would be someone angry...and...violent”. As can be seen from the above discussion, the colours that the women associated with HIV were relevant in that they often connoted danger. In the drawing below, note how the HIV is associated with colour red, and how the ARVs are associated with the colour yellow.



For many of the woman a strong theme was that of HIV being a criminal, an entity that acts as a thief and steals. Sphiwe described the HIV as “a thug and a thief” and chose to use red when drawing the virus. For Linda, HIV was also drawn using a red crayon and when describing it, she felt that, “...Let me say, it’s my cells. This virus is taking my cells”.

In addition to the HIV being viewed as a criminal, it was also felt to be attacking. This added another dimension to the idea of the virus being a thief, as well as that of something being stolen or taken away; HIV was depicted as violent and destructive. Nomvula described the HI virus as a “...deadly disease, a robber, and a killer, a criminal... in South Africa we call it Gintsa...a hijacker”. In both cases however, the overwhelming theme is that of something dangerous, destructive, and criminal.

“...umm...you know I can say the virus it might be something that can destroy the self. That destroys myself not to function the way it is supposed to” (Linda). HIV being seen as damaging seemed to take two paths: damaging a person both physically and emotionally. Linda spoke of the physical damage to her body:

...well let me say that what made me test was that my body was so weak. I was so weak, I was living in a flat and sometimes there was no lift. I used to climb the stairs very fast, but those days I was very tired. I couldn't even wake up early in the morning. I was just so weak. I was low energy so I couldn't do anything. I felt something is wrong in my body, I'm just not myself. Then there were things that lead me to test, I was getting what do you call, glands, I was having, and I was asking myself what is this?

This physical damage took many forms, with several of the women reporting it to have changed their complexion. In Thandi's drawing, she asserted that the HIV damaged her body physically in several ways:

...these spots are showing the true colours of the HIV. The body gets thinner. Your colour changes. You are not as bright as you were. These spots...it's like eczema. Like for me, the first time I was diagnosed the problem with me was my skin. I tend to be allergic, I was allergic before, but when I got HIV it was so bad. There were spots on my face. Then the thinness because I couldn't eat. Actually depression. I was so depressed, with me and HIV it was depression.

In addition to the physical damage, HIV was also reported to damage one on an emotional level. Thandi felt that HIV would be a horrible person "who destroys lives, marriages, families". Mafuwa also felt that HIV was both physically and emotionally damaging:

It affects the immune system. It doesn't work properly anymore. It becomes weak and you can easily become sick. So inside it has done a lot of damage. Mostly, I think I feel it emotionally, with thoughts. But yes sometimes I have pain. But I try to think that when I have pain, each and everyone could have that pain, that it's not necessarily the HIV. Whether it's a headache or stomach ache, I just tell myself it's just sickness.

In the above quote, Mafuwa conveyed the notion that HIV was able to damage more than the physical including one's emotional functioning. This idea was further supported by Thandi, who reported that it was the physical damage that lead to her being tested, but this was then compounded with emotional damage:

...I didn't even know that there was something bad in my body. I just went to the clinic because there was something in my throat. I couldn't swallow anything. I went to the clinic and they do some tests, and they said I must come back in a week's time. And I went back, that's when the bomb fell on top of my head and I was like is this true, because this notion of being not a good person a good wife...

5.4 "I am trying to cope but you just lose it sometimes": The Struggle to Cope

A major theme that pervaded all of the interviews was the conflict that emerges between needing and wanting to cope, versus not coping. Mafuwa's interview illustrated the conflict experienced

while trying to cope. She felt that HIV, "...is something stressful, but I am trying to cope. Am trying to cope but you just lose it sometimes". This same idea was experienced by Sipiwe who when speaking about her HIV said that: "...sometimes. Sometimes it feels worse than others". This was felt by several of the women in the study, with Linda feeling that it takes effort and time to get to a point where one is coping: "I got counselling for a long time and I am a little bit relieved. Anyway it can't be relieved just like that, as time goes on I think I will be ok but I'm getting there".

As reported by the women, it appeared to take time to move from a place of not coping to coping and following diagnosis it seemed that the women often felt they were in a state whereby they were not able to cope. Linda stated:

I wanted to grieve. I wanted to take this thing out of me. Then I cried really. I cried a lot... when I got home I cried. So he comforted me and said you know there is life after HIV. And I said no, I saw people dying and I thought am I going to be those ones that are dying. I had that vision of a dying person. I couldn't manage the stress at that moment, so he moved around looking for counselling. And he took me, said lets go for counselling. We did counselling together. But the problem now was that we were not working on top of that. The stress. It was so hard really.

Initially, Sipiwe was also not able to cope and in the beginning she reports that: "I was angry. I wanted to die. I tried to commit suicide. But, here I am now and I'm fine". This movement towards coping seems to often be facilitated via a process of acceptance.

...When I first found out I was devastated. I didn't believe I would be alive for even a week. I thought I am dead already. But as time goes on, the knowledge I got from the hospitals, I learnt I still have life ahead of me. This is not the end of it. I can still make it even with this HIV...Because now I am trying to cope with it. I have acceptance. I have accepted it in my life. And whenever I feel down and I talk to it and tell it 'no you won't take me down!

In the above extract, Mafuwa showed how coming to accept the HIV has allowed for her to cope with the virus, thus rendering her the one with power and control. In contrast to Mafuwa, Linda demonstrated how ARV's facilitated her transition from being powerless to powerful. She connoted HIV to Ammonia and said that even though it may be a powerful agent: "... you know you can neutralize that person, you an inject him and make him neutral. He has got power but if he slips, we inject him and he won't have that power anymore...He has a weakness".

Thus, by weakening the HIV, the person is strengthened and thus assumes the powerful position. Linda goes further to state that by accepting the HIV and assuming control, she has moved to a position where they have become friends: “I can say now that HIV is my friend...wherever I go I am with him... we were enemies he had the power to destroy me. I was weak. He was strong. But now we are friends and he is neutral. He can't do anything to me”.

Siphiwe also spoke of progressing from a state whereby the HIV is an enemy to where the HIV is a friend. Moreover, there seemed to have been a shift whereby initially the HIV was uncontrollable, but this transitioned into a state in which the HIV became more controllable and accepted, referring to it as ‘my HIV’. It seems that this sense of ‘ownership’ allowed for a greater sense of control, thereby facilitating the coping process.

The conflict between coping and not coping was also illustrated by the theme of feeling helpless and weak on the one end of the spectrum, and feeling strong and powerful on the other end of the spectrum. Mafuwa spoke of how difficult it is to remain positive and powerful, and how feeling weak can result in one's health declining: “... The mind is a powerful part because if you get stuck on the negative you will get more stressed and your CD4 will go down and you will get more sick. So, I think keeping a positive attitude is very important”.

Building on the idea that a positive attitude can impact upon a person's health, in turn, stress can result in a negative impact upon a person's condition. Nomvula reports that:

I think HIV, if in your mind you are always seeing it, always saying ‘I am HIV positive, I am gonna die’, the more the HIV positive becomes strong in your body, because stress helps HIV to move. You use your mind to be stressed. And if you are sad you also support HIV. Coz if you are stress free then HIV is powerless. If you are always happy and accepting everything you don't let HIV get stressed.

The women in this study, who live together in a women's shelter, reported that social support and being around those in a similar position can also facilitate the process of moving from a point of weakness to one of strength. Linda stated:

We kind of sharing our stresses and how we got through this, or else someone can advise you if you do this it will be fine, so that's how we live...[the shelter] made me accept a lot. Because the time I was outside you know people can't show their status. But when I

came here I realized oh all these people are HIV positive but they are living. Why am I so stressed? That's when I got relieved, and there is life after HIV.

In addition to support and acceptance, talking about the virus was also cited as aiding in the coping process. Nomvula showed how her power was restored through talking: “The more I talk the power I have... you know in my body, it's like I am the boss. I am the boss and HIV must take orders from me. (*Wags finger*) Stop this and stop that”.

As seen in the above quotes, several of the women reported speaking to the virus inside their bodies. Mafuwa reported telling it that “it won't drive me that I am the one that is going to drive it!”, while Thandi claimed that “before I didn't even want to speak to it. But now I can tell you that I can say to it ‘I am not created by you. Leave me alone.’ In both of these examples, the women reported having regained a sense of control over the virus.

Building on the idea of HIV as a thief, the women of this study also seemed to attribute aspects of loss to the HI virus. As mentioned previously, Nomvula referred to HIV as a “Gintsa...a hijacker”, implying that HIV steals certain aspects of your life, leaving you with less than before. These aspects may include “...lives, marriages, families” (Thandi). Hence, a person living with HIV may be susceptible to losing their current life but there also seems to be a sense of losing a future life. However, it is not only an emotional thief as described above, but HIV is also said to induce a physical loss. Several women in the study report losing a great deal of weight initially. This physical loss was often expressed by a loss of control over their bodies. In light of this thought, it is perhaps an acceptance of this loss that may assist in facilitating coping.

5.5 “This is not the end of it”: Process of acceptance

As seen in the above themes, it is the process of acceptance that affects how a person living with HIV copes to how powerless they feel. According to Linda, support was crucial in her path to acceptance:

... [The shelter] made me accept a lot. Because the time I was outside you know people can't show their status. But when I came here I realized oh all these people are HIV positive but they are living. Why am I so stressed? That's when I got relieved, and there is life after HIV... and now I have learnt to accept that you are here always. You won't go away so I have learnt to live with you.

However, it seems that the process of acceptance takes effort, and as mentioned by Linda, it was often support that helped to facilitate this process. Thandi agreed and stated: "...from the word go it is 'horror' 'death' 'isolation' 'depression', but the main thing is 'death'. For me it is death. Until you get counselled or you see someone else who is HIV positive and is living a progressive life".

Whilst some of the women seemed able to make progress on the continuum of acceptance, it became evident in the interviews that it is not only the people living with HIV that embark on this process, but also society and those surrounding the person. Nomvula spoke of how a lack of acceptance by society impacts upon the person living with HIV:

...they are afraid and if I tell them they will bring me down and tell me 'so and so died, so and so did this. You see this on your face, now you are on your way.' That's why we prefer to keep it. I am free to tell someone who is HIV because they will lift me up, but someone who doesn't know HIV will definitely kill me.

A further component in connection to the process of acceptance is the element of change that is experienced by those living with HIV. All of the women in this study reported having undergone a change in the way they view the HI virus from diagnosis onward. For Nomvula, the element of change was quite pronounced.

...in the beginning, I didn't believe I was HIV positive, and in the same time I was surprised how I am positive because I usually test and I am usually negative. So I went for testing and I was quite confident I was going to be negative, so when I was positive I didn't believe it. But as time goes on, I realized it is true and I must accept it, so that I can live because it is going to kill me if I reject it. Because it is really looking for those who doesn't accept it.

Thandi also felt there to be a change in how she accepted her HIV status and as mentioned previously, support is a facet that seems to help facilitate this process: "... it has changed a lot. Because now I am on medication. I am taking my ARVs every day. And I got counselled. Because you can get medication, but if you are not counselled and you know exactly what is this thing that is in your system, that is in your body, that is taking control of you, you will not be ok".

As discussed, the process of acceptance seems to exist on a spectrum, ranging from denial to acceptance. On perhaps the more positive end of the spectrum, a sense of the future seemed to emerge. Mafuwa stated: "Even though I am on ARVs, it doesn't mean I am going to get cured,

it's something I am going to live with for the rest of my life. So I have to accept it".

It is perhaps this sense of the future that allows for a person to remain connected to those around them.

5.6 "For my kid's sake": Isolation vs. being connected

The women in this study all experienced varying states of being either connected or isolated. Mafuwa displayed quite a high level of acceptance of her HIV status and as a possible result was able to feel connected to others around her, in particular her children. However, it might be worth noting that the converse of this may also be true, with the act of being connected allowing for a sense of the future to emerge. She stated: "...but now of lately I was feeling weak and I lost a lot of weight, so I thought of my CD4 count and I went to the clinic and they said yes it has gone to 187. So they advised me that I should start the ARVs immediately, so I had no choice. I thought about it and then I have to for my kid's sake".

Linda also mentioned the need to be responsible for her children, indicating a connectedness and lack of isolation. The act of being connected to one's children seemed to imply a connection to the future and a bond to life. Linda stated: "As for me really now, my stress is that I need to get a job. Because my son needs a proper place to stay. I need a proper place to stay. I just want to be responsible".

An overwhelming motif was the notion that the women and their HIV did not exist in isolation, and that when the wellbeing of their children was considered, the women were in some way forced to acknowledge the future. Mafuwa was able to feel connected to her children and thus responsible for them. Not only did she reach a state of acceptance herself, but she was also accepted by her family, and felt supported by them:

...when I was first diagnosed I was staying in Botswana. I was staying with an aunt of mine there, but I was born here (here referring to South Africa). The time I heard the news I went home, I was stressed. I told her, she was open somebody and I always had the freedom to tell her. If I am happy I can tell her and if something is stressing me I can always talk to her. So I just told her, I am from the clinic and they just told me this. And by then I was pregnant. So she just told me, well I was brought up in a family where we

pray, so she just told me to trust in god and god will help me. So we still need to believe in him. This disease you are going to live and we are going to see you with your kids growing and getting married.

The converse of being connected to others or the future is a state of isolation. The cause of this state of isolation or remoteness was at times seemingly as a result of the stigma experienced by the women. When asked about the process of disclosure Nomvula claimed that she,

...Didn't tell everyone. When I came from the clinic I didn't announce to everyone at all, I told my husband and my other friend first. And even my husband he didn't take, he doesn't want to discuss about it. He's ignorant. He doesn't even know his status anyway. He doesn't even know his CD4 count. Yeah but when I talk about it I feel strong and more confident.

In this instance, Nomvula was forced into a state of isolation as a result of the impending stigma she would receive. This could be looked at in contrast to the state of acceptance and connectedness that is found at the shelter:

... in this place, the more you mix with other people who have HIV, the more you start looking at this one and say oh she is coughing why not me. Here, not the location, there is no discrimination. You can talk about it anytime anywhere. You can even scream. But on the location you can't shout 'oooooh I am HIV positive!!' You would be afraid to say that to all people.

In sum, it seems that a continuum does indeed exist, with isolation and loneliness residing on the one end, and a sense of being connected residing on the other end.

5.7 "HIV is dark, but the ARVs are light": ARVs as good vs. ARVs as risky

The women of this study were all currently taking ARV's, and their attitudes towards the ARVs ranged from seeing the medication as good, seeing it as risky, to viewing it as both good and bad simultaneously.

A theme that emerged surrounding the ARVs was them being connoted as a type of security force, that which combats the thieving and criminal action of the HI virus. According to Mafuwa: "...the HIV is like the thief. So the ARVs make the immune system stronger so they can't steal anymore. Like the police maybe". Nomvula agreed with this line of thought and felt the ARVs to be "...attacking. They are trying to give life to the body, and life is coming up, the warning signs are going, the signs of danger are disappearing, and this HIV is suppressed".

Thus, in light of what was mentioned previously, many of the women felt the HIV to represent danger and the ARVs to represent life and safety. As demonstrated by the drawings, ARVs were represented with yellow, green, and white, all colours that seem to connote light and wellbeing.

However, a common theme that emerged from the interviews was also that of the ARVs being viewed as risky or dangerous. At times, the ARVs could be seen as good and helpful, but at other times they were seen to be something that was feared. For Mafuwa, who hesitant to take the ARVs:

...Yeah because at the time there was a doctor here, Dr..., and then my CD4 was still 260-something but she advised me to start taking ARVs. And then I wasn't really ready. Because of the things people always say about ARVs. That sometimes you can become more sick, or go crazy. So I was a bit scared really to take them because I didn't know how they would affect me or react. But now of lately I was feeling weak and I lost a lot of weight, so I thought of my CD4 count and I went to the clinic and they said yes it has gone to 187. So they advised me that I should start the ARVs immediately, so I had no choice. I thought about it and then I have to for my kid's sake.

It seemed that a factor contributing to the riskiness is the possible side effects that may result from the ARVs. This however, seems to be combated by education. However, a further factor contributing to the riskiness is the act of having to take medication for the rest of one's life.

Siphiwe stated:

...at first it was difficult for me to take them. I took them when my CD4 count was at 88. because I was scared of taking them for the rest of my life. I mean taking tablets in the morning and in the evening for the rest of your life. And I don't even know how long I have left. You know. I don't know. Maybe I will be 80 or a 100 or more than that I will be taking these tablets. As long as there is still no cure for aids.

It could also be posited that not wanting to take the ARVs was not due to the side effects, but rather to the act of having to be medicated. It appeared to be as a result of what taking the ARVs means about a person's strength and ability to cope. When asked about her suspicions around taking ARVs, Mafuwa stated that, "I think it is more just taking a tablet everyday that is scary. For the rest of my life? Because I was not used to that at all. I never took tablets, unless maybe a headache every now and then. For HIV though you need to take for the rest of your life". Thus, needing the take ARVs seems to perhaps substantiate the feeling of weakness, thus entrenching it.

In light of above, it seems that the process of taking ARVs also appears on as spectrum, ranging from viewing the medication as all good or all bad. However, once a certain level of education and acceptance is achieved, the ARVs are able to be viewed as a whole object that is comprised of parts both beneficial and risky. Nomvula was able to view the ARVs as “...good and bad. Here, there are some mothers on ARVs, and some were very very sick and then after ARVs they are fine”.

The question could be posed as to what allows for the ARVs to be seen as both good and bad at the same time. One explanation is the idea of the ARVs acting as facilitators between the person and the HIV. Linda felt that the: “...ARVs make us to be friends...we were enemies he had the power to destroy me. I was weak. He was strong. But now we are friends and he is neutral. He can't do anything to me”.

Thus, the ARVs perhaps act as both a physical and emotional support system allowing for a person to regain their control, power, and strength.

5.8 “When you leave they talk”: Stigma

The concept of stigma is somewhat pervasive in the world of HIV and was a prominent theme throughout this research. All of the women in this study had experienced some form of stigma, and prior to their own diagnosis, many of them had held those same views. Upon diagnosis, it seemed common that the women felt HIV was a certain death, however; it is perhaps with education and gained knowledge that these views became broader. Linda stated: “...Now I know I could still live for some years to come. Still see my son growing. Of which I didn't think before it was going to happen because the way HIV was presented I mean to us as human beings it was, you are the worst person in the world, you are just after somebody else's man” .

Whilst a sense of knowing seemed to improve how the person handles the stigma this seemed to only occur quite some time after diagnosis. According to the interviews, a fear of the views held by society seemed to affect the process of disclosure. Mafuwa stated:

Most times you have to research if the person you are going to tell if they can...is she going to be able to keep a secret or what, because maybe the news will start moving around to the people you didn't want to know. So in most cases you talk to someone you can trust...you need to be careful because some people gossip and some people don't accept people with HIV. They might even pretend to sympathize or feel for you when you are there, but when you leave they talk.

The above quote demonstrates the difficulty in disclosing to the community. However, it seemed that disclosing to one's family and extended family can bring the stigma closer. Sphiwe spoke of how she became an outcast in her family:

...Ya I think so. When I first told my family. Because I don't have much of a family, I was staying with the father of my kids, his family. I stayed there for then years and I was sick most of the time. His family, because you know they are Christians and they don't want to believe there is this AIDS. He's a pastor in the Church, so he was like I am the culprit for bringing it into the family. So I was an outcast then, to my in-laws. And then I told my family and they were like ok fine and they didn't want me anymore, because I had TB and Pneumonia and I think he thought I was dying or something. So they kicked me out. I had no place to go and I was on the streets for some time. And at that time...I hated AIDS. Because if it wasn't for HIV none of it would be like that.

Thus, the external stigma sometimes seemed to become internalised and the beliefs of others became to be the beliefs of the person who is the victim of the stigma. For Mafuwa, the stigma held by her family affected her coping and sense of strength. As a result, she was forced to leave her family and isolate herself. Stigma leading to isolation seemed to be a common experience for these women living with HIV. Mafuwa stated:

...but you know, but before they got knowledge about HIV because like my mom the way she was taking it, it was like she was thinking you can get it, it is flying in the air, or you can get it from touching somebody...someone wanted to kiss the little daughter on the forehead and my mother pushed them away. So you could see from her reaction that she was sending the message that don't kiss him or you will get AIDS...So she started to do funny things like putting my cup and my spoon over there, or I would find her gossiping with her kids saying don't drink from the cup that D is drinking with she is sick and you can fall sick. And sometimes when they would go to work they would take their Vaseline's with them. They would hide their toothbrush, lock the cupboards, and ya.....ya...

Building on the idea of stigma leading to isolation, in the same vein, stigma seemed to inhibit connectedness. This idea was clearly shown by Linda whose brother failed to accept her HIV positive status. Furthermore, her withholding of the information from her mother might also imply a sense of self-imposed isolation:

You can't be fat and be positive. You have to be skinny. He said I am lying, how can an HIV positive person be like you. I said I am even on ARVs. He said no show me the ARVs. I had to prove to him that these are the ARVs. He couldn't believe me. He didn't want to believe me, but after he accepted it and was there for me. He bought me food. If you are hungry call me and I will bring you something. It happened that god took him. He passed away. So what I haven't done is telling my mother. Because I know she has high blood pressure so I was afraid that she might get stressed.

5.9 The Gender of HIV

A further theme that became evident in the research was the engendering of the HIV by the women. For some of the women, when referring to the HI virus they associated it with the male gender. Linda, when speaking about what kind of person the HIV might be, stated:

...oooh ammonia. Ammonia. Yeah. But you know you can neutralize that person, you an inject him and make him neutral. He has got power but if he slips, we inject him and he won't have that power anymore

It is clear from the above quote, that for Linda, the HIV was male. Moreover, not only was the HIV seen as male, but it was also seen to have what could be considered masculine characteristics. For example, when speaking about the nature of HIV, Mafuwa reported that a personified HIV would be, "... someone who ruins people's lives. I think it would be someone angry...and...violent". Nomvula agree with her, referring to HIV as a "Gintsa...a hijacker". In South Africa, the gender of a hijacker or thief is stereotypically male. Thus, there seems to be a common theme of HIV assuming quite a dominant and perhaps male role.

For the women in this study, the men in their lives were often connoted with danger and ignorance. In addition, the HIV was also associated with danger. Thus, a parallel or similarity can be made in the fact that men and HIV were connoted with negativity and danger. For example, Nomvula stated that, "... even my husband he didn't take, he doesn't want to discuss about it. He's ignorant. He doesn't even know his status anyway. He doesn't even know his CD4 count." Thus, men's refusing to engage and think about HIV was a prominent concept held by the women.

As it was women reporting on the HIV, perhaps referring to it as male has a distancing effect, in that it once again make the HIV an 'other'. However, another notion is that both men and HIV

are associated as one and the same because for some of the women, as Thandi reported, “got this HIV through my husband”. Thus, they may be viewed as one entity as they originated from the same source. Furthermore, if the male is seen as dangerous and powerful prior to the HIV, the process of being infected with the virus via a man, may imply the positing of some of that danger into the women.

5.10 Conclusion

This chapter began with a brief exploration of the researcher’s reflexive response to the study. This was addressed due to the subjective nature of qualitative research. Each of the eight themes was then explored in detail, providing direct quotations from the interview so as to substantiate the theme. The following chapter includes a discussion of the results of this study in relation to relevant theory.

Chapter 6: Discussion

6.1 Introduction

The findings showed that the women of this study had each developed a complex set of relationships between themselves, the HI virus, and the ARVs. These relationships varied in terms of levels of acceptance of the positive diagnosis and the individual's perceived sense of coping. It was also found that these factors seemed to be influenced by the degree of stigma each woman had experienced, the amount of support she had received, and her ability to engage with the reality of HIV. Approaching the findings from a psychoanalytic stance provided a helpful framework through which to view the relationships that exist between the women, the HI virus, and the ARVs. To illustrate the dynamics of the aforementioned triadic relationship, it is helpful to explore the process of acceptance and coping from diagnosis onwards. Changes in these women's relationships with the HIV and ARVs in their bodies can be viewed as shifts and movements along what could be viewed as a continuum. To elaborate, on the one end of the continuum exists a state whereby a person is unable to think about and unable to engage with the personal implications of the virus; in a state in which they appear to feel helpless. On the other end of the continuum exists a state whereby a person is able to think about the virus and feel they have accepted the reality of their diagnosis, and they are now mostly coping. The themes that emerged from the study, namely: thinking vs. unable to think, HIV as danger, the struggle to cope, the process of acceptance, isolation vs. being connected, ARVs as good vs. ARVs as risky, stigma, and the gender of HIV, will be explained using psychoanalytic theory, particularly the theories of Klein and Bion.

When interviewed, the women were asked to draw the virus in their bodies. The aim of this task was to elicit from the women their perceptions and conceptualisations of the virus on a personal level. By asking them to draw the virus in their bodies, they were invited to engage with the HIV on a far closer and more personal level. The drawing of their bodies, the virus, and the ARVs, in some cases seemed to make it harder to rely on intellectualisation in order to talk about these relationships. Thus, by asking them to draw the virus in their bodies, the women were being asked to move away from external perceptions towards more of an internal conceptualisation.

6.2 Hijacked

For all of the women in this study, the HI virus was connoted with concepts that represent danger. The HIV in their bodies was conceptualised as being a criminal, an entity that acts as a thief, steals, and can at times be attacking. Thus, in addition to the idea of the virus being a thief, and something being stolen or taken away; HIV was depicted as violent and destructive. HIV was also seen to be damaging in both a physical and an emotional capacity. Overall, and particularly in the times leading up to and just after diagnosis, HIV was seen as totally or all bad. This can be explained using Kleinian theory, particularly the mechanisms of the paranoid-schizoid position.

Klein proposed two positions: the paranoid-schizoid position, and the more cohered depressive position. The move from the paranoid-schizoid to the depressive position is associated with an increasing integration of the self and object relations and the achievement of the depressive position is linked to a greater wholeness and sense of coherence of the self. For each of these positions certain defences are associated. In the paranoid-schizoid position, the immature ego is threatened by primitive anxieties, leading to the adoption of primitive defences such as splitting, projective identification, and idealisation (Klein, 1946). In this position, the immature ego is divided and split into two parts, one containing aspects of the self considered good, and the other containing aspects of the self that are considered bad. These parts are kept away from each other and aspects of each of these selves are then projected onto others creating good or loving and bad or persecutory object relationships (Klein, 1946). In contrast to the quite fragmented and split paranoid-schizoid position, when objects begin to be recognized as whole, a developmental shift is seen to take place, in that ambivalent impulses begin to be directed toward the object (Steiner, 1990). Steiner (1990) states:

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

In healthy development, normal splitting helps to organize chaotic experiences and provides primitive ego structuring and it is at this stage that the alternation between persecutory and idealized states are seen. This allows time for ego strengthening to occur, which then, in turn,

allows for greater integration and a greater tolerance of ambivalence (Segal, 1957). The sense of omnipotence that characterises the paranoid-schizoid position fades, and it is replaced by the recognition of one's dependence on another human being, who is now seen as a separate person. "The egocentric, narcissistic attitude, in which the infant conceives of objects in relation to himself, as being good or persecutory to himself, gives way to the relationship to another person seen as having her own feelings, problems, and relations to other people as well as oneself" (Young, 2000). Thus, "the infants shift from an ego-centred to an object-centred state, which is held to be the crux of the depressive position" (Likierman, 2001, p. 115).

As can be seen from the above discussion of Klein's principles, the terms 'primitive' and 'mature' are often used when describing the defences associated with particular positions. It is important to note that the term primitive, a commonly used term in psychoanalytic texts, refers to a state wherein the individual has adopted defences of a possible infantile and immature nature, those that are reminiscent of early infant functioning. In contrast, when referring to mature defences, this refers to a more cohered sense of functioning, whereby a person is able to tolerate both the love and hate they feel towards an object. These terms are not to be aligned or associated with derogatory connotations in which one position is superior to another. Both positions are necessary when facing stressors. Examples of such primitive defences include splitting and projection. These defences can be activated in adult life during times of stress. For example, primitive defences may be activated during a time when a person is faced with illness. A chronic reliance on predominantly paranoid-schizoid functioning is however considered less healthy.

When talking about the nature of the HIV in their bodies, the women displayed a tendency to split off the negative and bad parts of HIV and project them outward, in order to preserve the 'goodness' of the 'self'. Linda stated that, "...You know I am just like everyone else. I haven't changed or anything since I have realized I am HIV positive. The only thing that made me feel bad is how I got it. But anyway I got counselling for a long time and I am a little bit relieved". From this quote it is clear that when asked to consider the negative aspects of HIV and how they have impacted upon her life, Linda felt it too threatening to engage with her anxiety, and felt compelled to split off the negative parts and project them away from herself, thus leaving her

‘good’ and unaffected. Thus, the primitive defence of splitting has acted as a means to protect the ‘self’ against the anxiety caused by the HIV. In addition, the above quote shows how Linda was able to briefly express the possible guilt and/or anger that she may feel about being HIV positive, but there does seem to be a strong need to flee from this thought as she perhaps finds it more difficult to tolerate ambivalent feelings towards the virus.

When first diagnosed with HIV, individuals may initially draw on the more negative representations of HIV. These negative representations place the self under threat and in order to ward off the anxiety, primitive defensive positions may be activated (Rohleder, 2007). In light of the paranoid-schizoid functioning that is associated with the time shortly after diagnosis, another component of this position was displayed by the women in this study. Following diagnosis, the women seemed to merge with the virus; much like an infant is merged with their mother in early infancy. In a Kleinian sense, it is only once an infant reaches the depression position that they can differentiate themselves from the mother (Segal, 1973). “It is as if the virus comes to be identified with the person as a whole, casting a morbid pall over the thought of intimate exchange of any kind” (Smiley, 2004, p. 252). The women appeared to see themselves as merged with the virus, so that following diagnosis there was a pervasive feeling that they had merged with all the danger of the HIV and that this would lead to instant death. When commenting about her state post-diagnosis, Thandi claimed that, “I just had this big depression, this big fear that I’m going to die I’m going to die, and what about my son. All these horrible things and thoughts. And I might as well be dead now. I tried to deal with these emotions, and even though now it isn’t that easy. But then I dealt with these fears that I had”. From the above quotes, it is clear that the virus was very much feared by the women and caused a great sense of anguish. This can be explained by Klein’s concept of psychotic anxiety. “In early infancy anxieties characteristic of psychosis arise which drive the ego to develop specific defence-mechanisms” (Klein, 1946, p. 1). Bronstein (2001) defines this anxiety as “the fear of annihilation of life, which arises from death instinct within” (p. 113). This anxiety is thought to originate from the pain, discomfort, and loss of the intra-uterine state that are felt as an attack by the infant (Klein, 1952). Klein (1952) argues that the ego is present from the beginning of the infant’s life; however, the ego has not yet reached full development and is therefore under the control of the unconscious. The ego’s first activities are to defend against any anxiety experienced as persecutory anxiety via the use of

defences. It is this anxiety and fear for the loss of one's internal good objects that the ego has identified with, that initiate the employment of primitive defence mechanisms: splitting, denial, projection, introjections, projective identification, idealisation and disparagement (Bronstein, 2001). When first diagnosed, the women of this study seemed to experience a great deal of anxiety, at times perhaps reaching the intensity of Klein's psychotic anxiety which leads to the need to split and project.

As seen thus far, when first diagnosed, the women were only able to view the virus as dangerous and damaging. Furthermore, they seem unable to preserve the goodness of their 'self' without projecting the badness outward. Oftentimes, this badness is projected outward and finds itself reflected in the damaging and threatening stigma from others that is feared by the women. Thus, society then holds the badness and is viewed as persecutory. However, as the process of acceptance continues, which seems to be facilitated through being able to think and engage with the HI virus and in some cases, the addition of ARVs, so the person is able to view the virus in both a positive and negative light. Thus, there is a move towards the depressive position and the individual has moved from one end of the spectrum towards the other. During the interviews, it became clear that as the women were able to accept and cope with the virus, so they were able to mature in their thinking and feeling about the HIV. As mentioned previously, the term 'mature' in a Kleinian sense refers to a movement away from the use of primitive defences towards that of a more coherent and balanced way of functioning (Klein, 1952). The women were more able to tolerate their ambivalence towards the virus, enabling them to view the HIV as whole, something that is both loved and hated. When asked about the relationship she currently shared with the HIV in her body, Linda stated that:

"How can I put this? I can say now that HIV is my friend...

It's your friend? Can you tell me a bit more about that?

...well wherever I go I am with him".

Thus, Linda was able to reach a state whereby she was able to acknowledge and tolerate the HIV as being something both good and bad. She was more able to see it as a whole object, without splitting off the negative aspects of it and projecting them outward.

As is evident in the above quote, Linda referred to the HIV as belonging to the male gender. This was a common theme throughout the interviews and several of the women attributed male characteristics to the HI virus. As this study consisted of women, perhaps referring to HIV as male had a distancing effect, in that it once again made the HIV an ‘other’. Furthermore, some of the women, such as Thandi reported that she “got this HIV through my husband”. In a Kleinian sense, the HIV and men may be viewed as a single bad object, and the process of being infected with the virus via a man, may imply the depositing of some of that danger into the woman. This newly deposited ‘badness’ will then need to be defended against and projected outward. This process is characteristic of the paranoid-schizoid position.

Elements of the paranoid-schizoid and depressive positions are visible in the drawing below where initially the middle of the body was filled with red (representing the HIV as being all bad and consuming). When discussing ARVs later in the interview, Nomvula decided to add the ARVs into the drawing. Thus, the red/HIV is still visible, but this is combated or eased with the green (representing the ARVs).



For the women, a common conceptualization of the HIV and ARVs in their bodies, was an initial invasion of danger, often represented with the colour red, followed by the danger being controlled by the ARVs, which were often shown using green. Thus, both positive and negative attributes regarding the state of their current relationships with their HIV and ARVs are able to be held in mind at once. Prior to the ARVs, paranoid-schizoid functioning is prominent as the body and the HIV are viewed as all bad. However, once the ARVs were added, depressive functioning is more prevalent as both the HIV and ARVs are seen to co-exist, implying a presence of both 'good' and 'bad' simultaneously. When functioning from a more depressive position, the women also seemed more able to view their bodies as both linked to but separate from the HIV.

As discussed previously, the concept and process of othering, which is perhaps synonymous with HIV, is underlined with a flavor of separateness, often resulting in isolation. This is perhaps more true when exploring HIV in South Africa. As mentioned in Rohleder (2007):

Since the election of a democratic government in 1994, South Africa has attempted to create a unified, single South African identity. Popular discourses that prevail are the notion of South Africa as being 'a rainbow nation' – one nation of many races and cultures (Tutu, 1994). For many years, a slogan of one of the national television channels has been 'Simunye', which translates as 'we are one'. Such discourses encourage the development of a united South African identity. However, superimposed on this post-apartheid identity, is the HIV epidemic which has fuelled major divisions in South African society (p. 204-205).

The converse of being connected to others or the future is a state of isolation. However, the cause of this state of isolation or remoteness was at times seemingly as a result of the stigma experienced by the women. According to Smiley (2004):

In part, this trauma results from debilitating stigma, creating distance from partners, friends, or family members as well as other social and psychological barriers...Such isolating effects of the virus drastically restrict the possibility of intimacy not just because of its association with sexuality, but also by inhibiting the closeness that profoundly textures relationships (p. 252).

Thus, the effects of stigma are often the origin of the isolation experienced by the women. "...it is clear that the women's HIV diagnoses render them discreditable, if not discredited, and make them vulnerable to significant suffering. This suffering includes feelings of contamination, experiences of rejection when they disclose their HIV status and physical symptoms" (Scott, 2009, p. 464). The concept of stigma is somewhat pervasive in the world of HIV and was a

prominent theme throughout this research. All of the women in this study had experienced some form of stigma, and prior to their own diagnosis, many of them had held those same views. Upon diagnosis, it seemed common that the women felt HIV was a certain death, however; it is perhaps with education and gained knowledge that these views became broader. Thus, as they approached the depressive position and were able to cope, so did the impact of the stigma dissipate. Thus, it seems that the degree to which a person handles the stigma also lies on a continuum, ranging from how isolated the person is as a result of the stigma to how connected they are to others in spite of this and how accepting they are themselves of HIV.

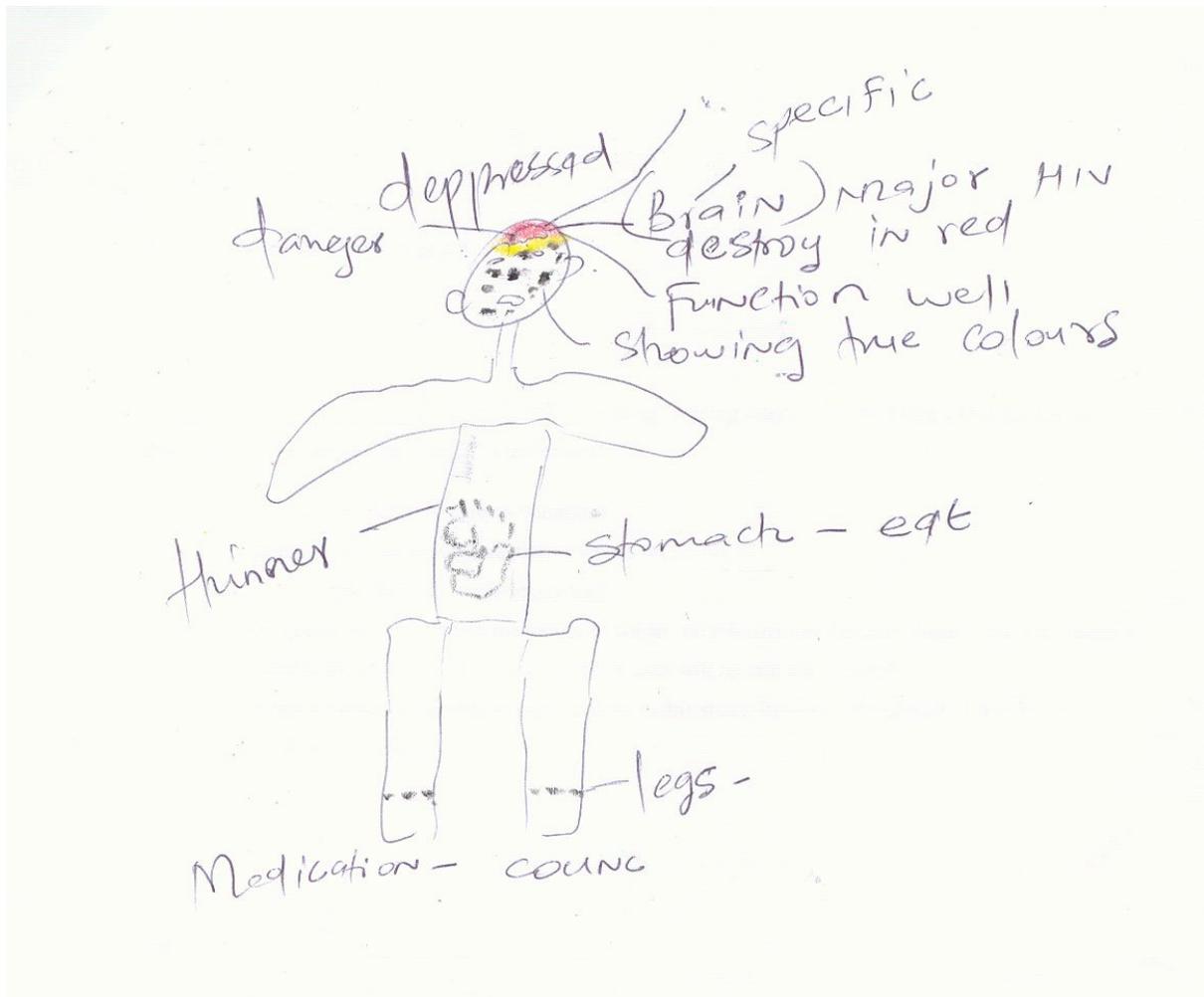
Having mentioned that education, knowledge, and support help to alleviate the effects of stigma, it may be useful to consider aspects that negatively impact how a person handles stigma. For some, the external stigma sometimes seemed to become internalised and the beliefs of others become to be the beliefs of the person who is the victim of the stigma. For Mafuwa, the discriminating beliefs held by her family affected her coping and sense of strength. As a result, she was forced to leave her family and isolate herself. As mentioned, stigma leading to isolation seemed to be a common experience for these women living with HIV. One way to understand the effects of this process of forced isolation or exile is to resurrect the notion that following diagnosis an individual is in a sense merged with the virus and all that it connotes. To clarify, following diagnosis an individual may be exposed to stigma held by their family or community, which may result in them being exiled. The person is exiled because they are HIV positive, so by the family rejecting the virus, they are at the same time rejecting the person. At this particular point in the process, the person is functioning from a paranoid schizoid position and is unable to view themselves as separate from the virus. The possibility exists that the initial merger or lack of separation with the virus is then reinforced by this rejection, as the person may be unable to differentiate what was rejected: the individual or the HIV.

The process of disclosure seems to highlight how an individual handles the stigma associated with HIV. It seemed that disclosing to one's family and extended family can bring the stigma closer thus perhaps making it increasingly persecutory. The concept of 'othering' can be used to explore the role of stigma in the relationship between an individual and the virus. As discussed previously, when a person is diagnosed with HIV they are sometimes forced to incorporate the

negative associations that are connoted with the virus. However, these are sometimes too threatening to the 'self' and are then projected outward onto society who may then be viewed as persecutory. Hence, a situation may arise whereby the stigma that is usually attributed to an external object is now reversed and projected internally. "When a person becomes HIV-positive, the individual becomes the recipient of these social projections. They are forced to incorporate the split-off aspects attributed to the 'Other', internalizing the stigma attributed to them (Rohleder & Gibson, 2006, p. 28). In light of this process, disclosing to friends and family may bring the persecutory attitudes closer. When exploring HIV related stigma in South Africa, it is important to keep in mind that whilst stigma as a result of projections does exist, so too does the notion of reality-based stigma. Judge Edwin Cameron in an interview, proposed two dimensions to stigma: external and internal dimensions. The external dimension manifests in discrimination against and ostracism of persons living with Aids, sometimes culminating in extreme violence, and the internal dimension consists of feelings of shame, contamination and self-blame that someone with HIV or at risk of HIV feels within him- or herself (Gosling, 2008, p. 265). This research supports the concept of external and internal stigma, in that the women of this study displayed evidence of both. In terms of external and real stigma, the women reported experiencing discrimination due to their HIV positive status, but also seemed to project their own negative views of HIV outward onto others so as to not let the badness contaminate their selves. In addition, the internal stigma as described by Gosling (2008) was also reported.

6.3 Security: The Process of Defending and Strengthening the 'Self'

Initially, for some of the women in this study it was difficult to think about the HIV, with some claiming that they not previously thought about the HIV inside their bodies. During the interviews, it became evident that many of the women struggled to engage with the concept of thinking about the HIV inside their bodies. For example, in the drawing below Thandi was unable to just draw the HIV in her body. She seemed to feel the need to move away from a purely visual presentation of the virus to more of a knowledge-based conceptualisation.



It seemed that following diagnosis there was an initial period whereby the women were particularly unable to think about the virus and that the origin of this inability may have stemmed from a lack of knowledge about the virus itself, as well as from the use of more 'primitive' defences, such as denial, in order to cope with the shock of diagnosis, which is reflective of Bion's (1962) -K. This initial lack of knowledge, to which many of the women refer, seemed to enhance a sense of helplessness, which may have further prevented an ability to engage with the reality of their status. Being unable to think about HIV also became apparent when going to get tested, and perhaps worked as an inhibiting factor (i.e. creating an avoidance towards getting tested), defending the women against the prospect of being HIV positive. It could be proposed that engaging with thought surrounding the virus during the initial stages may be too threatening. It came to the fore during the interviews that some of the women, instead of thinking about the HIV on a personal level and inside their bodies, were only able to intellectualise about the HIV. Thus, they were able to think about it from an outside or external perspective, but were unable to

grapple with it on a personal level. For example, some of the women claimed that they were only able to accept their HIV positive status once they had been educated about the virus. This notion of intellectual understanding and knowledge, whilst positive in that it allowed for the virus to be thought about, may also have acted as a defence mechanism, distancing the women from having to engage with the HIV on a personal level. This was evident in the women's inability to think about the HIV without referring to an external point of reference. For example, when asking Thandi how she felt following diagnosis, she admits to being angry, but was unable to stay with this emotion and resorted to explaining how she felt using medicalised language suggestive of the knowledge she has acquired:

I was angry. Very angry. I was angry at the first person who got diagnosed a long time ago. Where does this come from! I mean, what is this thing? They tried to explain to me, my doctor told me, I don't know if it is true or not or just a story. That's why it is called Human Immunodeficiency Virus, because it was from somewhere I am not sure which country, and they were fighting with the chimpanzees or the monkeys, and when they scratched them this blood enters their body and when the sores were healed this thing is already in their blood or systems. So when they sleep with their partners, this thing multiplies. The sad part of this HIV is that it doesn't show the moment it enters your body. That's the sad part of it. Because if you knew now you were getting this thing then...

However, the process of intellectualising can also be seen in a positive light. The way in which intellectualising or the gathering of knowledge seems to be useful, is that for several of the women, the possession of knowledge about HIV allowed for themselves and their families to begin to be able to engage with the virus and the stigma that surrounds it. Thus, the possession of knowledge allowed for the virus to begin to be thought about, thus facilitating a movement from a state of helplessness towards that of acceptance. The converse of this also seemed to be true, whereby a lack of knowledge seemed to inhibit the person and their family's ability to think about the HIV. This lack of knowledge was also associated in the women's minds with fear, stigma, and discrimination. For example, Nomvula spoke of how a lack of knowledge was linked to stigma and fear. Nomvula stated that:

I think at the location if I just scream and tell people, tell everyone that I am HIV positive, some they don't know about this HIV thing. So if I scream and tell them at the end of the day they will pull me down. They will bring that stress back... they will bring those fears back. They will give me their fears.

Links between knowledge and stigma have been explored through the psychoanalytic concepts of splitting and projection. In relation to HIV stigma in communities, previous research has found splitting to be a common defense mechanism that is utilized. The first occurs between the 'self' and the 'other'. For example, for the individual who is uninfected with HIV, the 'self' is seen as 'good' and the 'other', the person living with HIV is 'bad' and is therefore rejected. Hence, the 'self' remains the pure primary self that does not have HIV, and in order to defend this pure and uninfected 'self' the 'other' becomes those that are infected with the virus (Rohleder, 2007). Other research done with HIV positive individuals, proposed a slightly different concept whereby the 'self' is the one who is infected with the virus, who is responsible for knowing their status and is thereby good, and the 'other' refers to those who probably have the virus but are unaware of their status and are therefore bad (Rohleder, 2007). Thus, the defense mechanisms of splitting and projection are employed in order to preserve the 'self'. In the latter concept, even when the 'self' is infected with the HI virus, an othering process still occurs whereby the 'others' are seen as bad due to their ignorance. Thus, for an HIV positive person to preserve a good and pure 'self' they may need to educate themselves and engage with the virus. Conversely, a lack of knowledge about the virus, which may be held by society and perhaps their families, then comes to be associated with the bad and impure 'other'. Thus, the uneducated become entities that, although feared on a more conscious level, are unconsciously devalued. As cited in Rohleder (2007):

He said he found the support group frustrating and irritating because 'the other people in the group don't know much'. He constructs a link between HIV and 'the uneducated', and positions himself in defence of this. He stressed how much knowledge about the disease he had acquired and he feels he knows more than 'them', and so he found it very unhelpful (p. 408).

The above quote illustrates the need to preserve a good 'self' and shows how the negative aspects that are a threat to the self are then projected outward onto the 'other'. As mentioned previously, when first diagnosed, the women often resorted to primitive defences such as splitting and projection. These primitive defences according to Bion (1959) seek to destroy anything that functions to link one object with another. Thus, by using these primitive defences, the women have prevented the ability to think about the virus, which inhibits the ability to the HIV on a personal and emotional level. Thus far, the discussion has explored how being able to think about the virus perhaps allows for a certain degree of acceptance.

To clarify, intellectualisation, which is considered a healthy defence, does indeed serve a necessary purpose in that following diagnosis it helps to cohere a person's sense of self and assist them in coping (Kaplan and Sadock, 2007). However, this initial coping is most likely to be purely functional and superficial in some way. What this study is proposing however is that intellectualisation is being overused as a defence by these women. Rather, intellectualisation and the acquiring of knowledge seems to be used as a defence mechanism as a means to avoid dealing with the emotional implications of being HIV positive. In a study by Hollway and Jefferson (2000), they argued that individuals align themselves with specific social discourses and view themselves in relation to these constructions as a means to defend against anxiety created by threats to the self. Thus, an individual would "defend against discourses that threaten the self, and rather draw on discourses that may affirm their sense of self and identity" (Rohleder, 2007, p. 402). For example, in this study, many of the women drew on medical or knowledge-based discourses, so as to align themselves with something perhaps they see as being controllable or understood. This would assist in defending against the anxiety of seeing themselves as aligned with discriminatory discourses that would threaten their sense of self. This line of thought helps to explain how negative representations of HIV are defended against, as a means to preserve a positive self-identity and slowly process the emotional implications. The findings of this study seem to suggest that the defence mechanism of intellectualisation results in avoidance, protecting the person from experiencing an overwhelming sense of helplessness and allowing them to cope. It could be posited then that this defensive process initiates the movement from one end of the spectrum to the other: from a state of helplessness to that of coping. In reference to the women in this study, intellectualising seems to be doing just that, initiating some form of movement along the continuum. However, the benefits of this defence seem to only reach so far, with some of the women appearing to become stuck. The women are indeed moving from the one end of the continuum towards the other but may not be reaching full acceptance possibly because of the use of intellectualisation, which inhibits the women being able to process their emotions on a personal level.

It is helpful to consider Bion's theory of thinking to explore the notion of the women finding it difficult to process their emotions surrounding HIV on a personal level. In object relations, what is thought to make up the link between objects is emotion or feeling, however, for Bion (1962)

another link between objects is thinking. Bion's major concern was the application of thought to emotional experience, and he states that an emotional experience cannot be conceived of in isolation of a relationship (Symmington & Symmington, 1996). Bion's concept of 'thinking' is not referring to the frequently used term associated with cognitive processes of the brain, but rather to the process by which an individual attempts to know himself or another. According to O'Shaughnessy (1981): "His concern with thinking is as a human link, the endeavour to understand, comprehend the reality of, get insight into the nature of, etc., oneself or another. Thinking is an emotional experience of trying to know oneself or someone else" (p. 81). Klein laid a crucial foundation for this view by differentiating between "intrusive curiosity, stimulated by a voyeuristic need to 'know' in order to master and control, and a more enlightened desire to understand; something more akin to a thirst for knowledge, in the interest of growth rather than of mastery" (Waddell, 1998, p.102). It is this interest in growth that differentiates the emotional knowing characteristic of a K link from the desire to fill the intellectual storehouses of the mind with knowledge as a commodity, enabling oneself to avoid personal meaning and growth (Waddell, 1998). In contrast to K, Bion allocated the symbol -K, which he conceived of as a resolve not to know. Thus, the women in this study seemed to predominantly adopting -K position in that they seemed to be determined not to know or think about the HIV in their bodies. According to Bion (1962) "...an emotional experience that is felt to be too painful may initiate an attempt either to evade or modify the pain according to the capacity of the personality to tolerate frustration" (p. 48). According to Bion (1962) when there is "a need to be rid of emotional complications, of awareness of life and of a relationship with live objects" (p. 11), knowledge of painful internal and external reality is evaded. Thus, the women are unable to think about the HIV and therefore are unable to process their emotions on a personal level. This notion was supported by several factors during the data collection phase and analysis process of this study. It became clear that the women in the study struggled to process their emotions surrounding their diagnosis as they tended to use intellectualisation in a manner that had become maladaptive; the use of this defence prevented them engaging with the virus on an emotional level. This manifested in them being reluctant to draw the virus in their bodies, and in their adopting of medicalised language. Thus, there was little evidence of emotional processing. Furthermore, when comparing the women's perceptions of the virus in their bodies post diagnosis and at the time of the interview, shifts were noted but these shifts seemed to be marked

by an intellectual growth, rather than by an emotional growth. Thus, for some women acceptance and coping was associated with an increased knowledge base, rather than an awareness and acknowledgement of them living with HIV.

A sub-theme that emerged within the theme of thinking about HIV was that of the power of the mind, and the power of being able to think about the HIV, affecting the course of the virus itself. For some women, being able to think about the HIV allowed for them to gain some control over the virus, thus making them more powerful. Thus, in a sense being able to think about the virus allows for the 'self' to become stronger. It may be posited in this case that the person living with HIV is the primary person or the 'self', and the virus is 'the other' that is becoming weaker in relation to the 'self'. In a panel discussion that focused on people's encounter with HIV/AIDS it was noted that for some people, The HI-virus was compared to a malevolent trickster type energy that used ingenious means to gain access to the host. It was an impersonal agent seeking only its own survival but if left untreated would ultimately result in the death of the host (Gosling, 2008). In this study, the HI-virus was also seen as separate from the individual, and was viewed as a negative other. So, the HIV itself may be seen as 'the other' that is the invader, and instead of projecting outward, the vulnerability the women feel may be projected inward onto the virus.

What is interesting to note and is endemic to living with HIV in South Africa is the approach of the South African government to the HIV epidemic.

The Minister of Health, Dr Manto Tshabalala-Msimang has been argued by some to be resistant towards the provision of antiretroviral therapy (ART). She foregrounds instead a traditional 'African' method of treatment using indigenous foods such as the African potato. In addition she advocates the use of nutritious foods, such as garlic, lemon and olive oil in the care of persons with AIDS (Rohleder, 2007, p. 403).

In light of the role of knowledge in the process of acceptance and coping, it could be imagined that living in South Africa with HIV could be inhibiting. When the environment wherein one is living is providing conflicting education and knowledge, it may become increasingly difficult to think and engage with the virus.

An element briefly mentioned as a factor that aids the process of acceptance and the movement from a paranoid-schizoid position to that of a more depressive position, is the notion of ARVs. The women of this study were all currently taking ARVs, and their attitudes towards the ARVs ranged from seeing the medication as good, seeing it as risky, to viewing it as both good and bad simultaneously. A theme that emerged surrounding the ARVs was them being connoted as a type of security force, which combats the thieving and criminal action of the HI virus. Thus, in light of what was mentioned previously, many of the women felt the HIV to represent danger and the ARVs to represent life and safety. Thus, several examples of splitting occurred when exploring HIV and ARVs simultaneously. Firstly, when the topic of ARVs was introduced it seemed that some splitting did occur. The HIV was seen as all bad, and the ARVs were viewed as all good. However, the women in the study also seemed to exhibit splitting within the ARVs in that sometimes they were viewed as good and sometimes they were viewed as risky. Thus, whilst the ARVs helped to facilitate the process of coping and in contrast to the HIV were seen as good, at times they were seen to be risky.

In contrast to the ARVs being viewed as all good, a common theme that emerged from the interviews was also that of the ARVs being viewed as risky or dangerous. At times, the ARVs could be seen as good and helpful, but at other times they were seen to be something that was feared. It seemed that a factor contributing to the riskiness is the possible side effects that may result from the ARVs. This however, seems to be combated by education and knowledge. However, a further factor contributing to the riskiness is the act of having to take medication for the rest of one's life. When discussing her experience of starting ARV treatment, Sipiwe stated that, "I think it is more just taking a tablet everyday that is scary. For the rest of my life. Because I was not used to that at all. I never took tablets, unless maybe a headache every now and then. For HIV though you need to take for the rest of your life". Linda agreed with her saying, "... You know I didn't want to take them because there was this thing that every day I need to tablets...in the morning in the night. I had that mind".

Thus, the women felt that it could also be posited that not wanting to take the ARVs was not due to the side effects, but rather to the act of having to be medicated and what that implies. In a study by Kremer et al. (2006) that explored the role of mind-body medicine, an approach to

healing that hypothesizes that thoughts, beliefs, and emotions affect health, they found that a belief in this connection may discourage some people living with HIV to take ARVs. In particular, it discouraged those who perceived the need to take ARV treatment as a failure of them in not being able to control the disease. This study supported this notion, and as seen in the quotations above, a factor preventing the women taking ARVs appeared to be what taking the ARVs might mean about a person's strength and ability to cope.

In light of above, it seems that the process of taking ARVs also appears on as spectrum, ranging from viewing the medication as all good or all bad. However, once a certain level of education and acceptance is achieved, the ARVs are able to be viewed as more whole objects that are comprised of parts both beneficial and risky. One theme exists of the ARVs acting as facilitators between the person and the HIV. Thus, the ARVs perhaps act as both a physical and emotional support system allowing for a person to regain their control, power, and strength. When an individual is able to view the ARVs as both good and risky, it could be posited that they have reached a depressive position. In this position there is a change in the nature of the defences that are present. Split feelings of 'love' and 'hate' are now able to come together. This more reconciled position is known as the depressive position. Ambivalence is now felt towards the complete object (Klein, 1952). In this study, several of the women were able to view the ARVs as simultaneously beneficial and risky. For example, Mafuwa refers to the ARVs as, "...sometimes they shake you a bit but I can deal with it". Thus, she was able to tolerate the opposing views, implying that she possesses depressive functioning skills.

6.4 Emotional Processing

However, the movement from one end of the spectrum to the other, from the paranoid-schizoid towards the depressive position, can be challenging. A major theme that pervaded all of the interviews was the conflict that emerged between needing and wanting to cope, versus not coping. This was felt by several of the women in the study. As reported by the women, it appeared to take time to move from a place of not coping to coping and following diagnosis it seemed that the women often felt they were in a state whereby they were not able to cope. In this state, there seemed to be an all-or-nothing feeling, which is characteristic of the paranoid-schizoid position. "Using Kleinian theory and the developmental move from the paranoid-

schizoid position to the depressive position, they argue that there is a need to acknowledge both the negative (bad) and positive (good) consequences of HIV to allow for a more integrated sense of self “(Rohleder, 2007, p. 410). This study supported the above claim, in that one the one end of the continuum there was an all-or-nothing style of functioning, in that following diagnosis the women were unable to cope. However, on the other end of the continuum lies a state where both coping and not coping are able to be tolerated, accepted, and acknowledged. This being said, for the women of this study a depressive position was difficult to achieve.

As mentioned briefly above, in addition to education and knowledge, ARVs also seem to assist the process of acceptance, facilitating the transition from being powerless to powerful. Thus, by weakening the HIV, the person is strengthened and thus assumes the powerful position. Thus, the person living with HIV becomes the primary person or the ‘self’ that is infused with power, and the virus becomes ‘the other’ that can in some sense be dominated. However, this state still seems to be within the paranoid-schizoid position, whereby the virus is still being viewed as predominantly negative, however, it could be the case that this step of assuming some form of control may be necessary in the process of acceptance and in moving toward the depressive position.

Several of the women in the study commented that by accepting the HIV and assuming control, they had moved to a situation where they have become friends, implying a movement away from viewing the HIV is an enemy towards viewing the HIV is a friend. Moreover, there seemed to have been a shift whereby initially the HIV was uncontrollable, but this transitioned into a state in which the HIV became more controllable and accepted, referring to it as ‘my HIV’. It seems that this sense of ‘ownership’ allowed for a greater sense of control, thereby facilitating the coping process. When exploring the mechanisms of this process, the depressive position was a helpful tool. It may be posited that as the women move towards the depressive position, their egos became more cohered and robust. As a person negotiates their way through paranoid-schizoid position towards that of the depressive position, the ego is defended against by the primitive defence of splitting which helps to organise these experiences. Whilst this is occurring, time is granted for ego strengthening to occur, which allows for greater coherence and a greater tolerance of ambivalence (Segal, 1957). As the splits occur less frequently and cohesion is

reached, the depressive position is gradually achieved. With a more robust ego, they are able to take their projections back, allowing for themselves to now take ownership of both the positive and negative aspects of the HIV. They are therefore capable of referring to the virus as ‘my HIV’. To elaborate and as mentioned previously, following diagnosis the need to split was essential as it functioned as a protective mechanism in defence of the ego. However, as the women were able to cope, so they moved along the continuum towards the depressive position. They were able to reach a state whereby they could tolerate or hold in mind both the negative and positive attributes of the HIV. “Steiner (1990) writes that in Klein’s theory projective identification is reversed through mourning and that it is through this process that parts of the self previously ascribed to the other are returned to the ego” (Bain, Gericke, & Harvey, 2010). It seems that a sense of control plays an important role in the process of acceptance. This may be due to the fact that to assume control there needs to be a prerequisite power hierarchy in place, and it is only when the power is in the hands of the individual, and not the virus, that the coping process can continue. Furthermore, in order to create a hierarchy there needs to first be a clear distinction between ‘self’ and ‘other’ to enable some form of separateness to occur. This idea of separateness links to the notion that following diagnosis, the person and the HIV are one and the same; they are merged much like an infant and its mother. As mentioned earlier, following diagnosis an individual is most likely to be functioning from a paranoid-schizoid position, whereby they and the HIV are one and the same. It is only as they approach the depressive position that they are able to view themselves as separate to the virus. In sum, an individual in the depressive position has managed to view the HIV as both positive and negative, enabling themselves to separate from it and regain control.

To elaborate, in order to achieve the depressive position, loss needs to be negotiated. One of the most crucial elements according to Klein is not as much the integration of the part objects, but rather the dramatic response that the integration triggers in the infant (Likierman, 2001, p. 113). The infant recognises that his external world is flawed and imperfect, and aggression, ambivalence, and a depressive state is mobilised (Likierman, 2001). The infant begins to feel a primitive guilt, which is rooted in the fact that the loved object is now lost as a result of the one’s own aggression. To elaborate, the good and ideal breast from early infancy is now lost and unavailable, and in its place is a whole mother that is comprised of both nurturing qualities and

frustrating limitations (Likierman, 2001). The infant mourns as he has lost the ideal loved object. Thus, for the women of this study, in order to be as separated from the HIV, they need to have acknowledged and mourned the losses they have experienced as a result of being HIV positive.

Building on the idea of HIV as a thief, the women of this study also seemed to attribute aspects of loss to the HI virus. Nomvula referred to HIV as a “Gintsa...a hijacker”, implying that HIV steals certain aspects of your life, leaving you with less than before. Hence, a person living with HIV may be susceptible to losing their current life but there also seems to be a sense of losing a future life. However, it is not only an emotional thief as described above, but HIV is also said to induce a physical loss, which was often expressed by a loss of control over their bodies. In light of this thought, it is perhaps an acceptance of these losses that may assist in facilitating coping. To summarise, there is a clear shift from the paranoid-schizoid position towards that of the depressive position, and it seems that this shift is often facilitated through knowledge, education, acceptance, and ARVs. Through the process of acceptance, a person is able to reach the side of the spectrum where they are okay with both coping and not coping with HIV. In this position they are able to relate to the HIV as a whole object and are then able to differentiate themselves from the virus, thus rendering it an ‘other’.

As discussed, the process of acceptance seems to exist on a spectrum, ranging from denial and helplessness on the one end, to acceptance and coping on the other. To elaborate, the women seem to move from a state where that is dominated by all-or-nothing thinking, where because they are HIV positive they are without hope and feel they will die. On the other end of the spectrum, a more cohered way of thinking pervades, where the women have accepted that they are HIV positive and can live with the virus. On the more cohered end of the spectrum, a sense of the future seemed to emerge. It is perhaps this sense of the future that allows for a person to remain connected to those around them. It could be argued that as an individual approaches the cohered end of the spectrum and is able to transition from a state of denial to that of acceptance, they are able to reach the depressive position. In this position they are a whole and intact person and they are able to view themselves in relation to and separate from others. Thus, an awareness of others and an awareness of the future are able to emerge. The women in this study all experienced varying states of being either connected or isolated. Mafuwa displayed quite a high level of acceptance of her HIV status and as a possible result was able to feel connected to others

around her, in particular her children. An overwhelming motif was the notion that the women and their HIV did not exist in isolation, and that when the wellbeing of their children was considered, the women were in some way forced to acknowledge the future. This notion is clearly displayed in Thandi when discussing how she views the relationship between HIV and the ARVs, "...Because the HIV is dark, but the ARVs are light. Now I know I could still live for some years to come. Still see my son growing."

6.5 Sharing my Body: Acceptance

A concept that has been mentioned throughout this discussion is the process of acceptance and the importance of its role in facilitating the movement from the paranoid-schizoid towards the depressive position; from a state of powerlessness to that of control and coping. It is necessary at this point to differentiate between what is understood by the term 'acceptance' in relation to HIV, as it seems to have a multitude of meanings. For some of the women, it seemed that acceptance referred to being to cope completely and being able to function without ever experiencing helplessness. Mafuwa explained how she has moved from a state whereby she had not accepted the HIV, to a state where she has, "When I first found out I was devastated. I didn't believe I would be alive for even a week. I thought I am dead already. But as time goes on, the knowledge I got from the hospitals, I learnt I still have life ahead of me. This is not the end of it. I can still make it even with this HIV". However, for the researcher, coping entailed a more Kleinian stance, with an individual being able recognise that sometimes they are able to cope, and sometimes they may feel helpless. For this notion of acceptance, being able to acknowledge this oscillation along the continuum is vital.

However, it seems that the process of acceptance takes effort, and as mentioned by Linda, it was often support that helped to facilitate this process. A further component in connection to the process of acceptance is the element of change that is experienced by those living with HIV. All of the women in this study reported having undergone a change in the way they view the HI virus from diagnosis onward. It seemed that as the process of acceptance moved further from denial and closer to acceptance, so does a person grow in their ability to see themselves as separate from the HIV. The women in this study all perceived themselves to have moved from a state whereby they were unable to cope to a state whereby they could. Thus, there seems to be a

self-reported movement from a paranoid-schizoid position to a depressive position. When talking of how her relationship with her HIV has changed, Thandi stated that, “I am in control now. Now I am on ARVs, and now I can control it and not for it to control me”. This movement allows for them to be a whole and intact person and they are then able to distinguish themselves from the negativity associated with HIV. They are then able to view themselves in relation to the HIV rather than as part of the HIV.

6.6 Conclusion

This chapter provided a discussion of the major themes that were elicited from the themes and linked them to the relevant literature. In sum, the major themes were viewed through a psychoanalytic lens and explored from an object relational perspective. The following chapter will present the main findings of this study.

Chapter 7: Conclusion

7.1 Introduction

The aim of this chapter is to present the broad conclusions that can be drawn from this study.

The chapter begins with a summary of the main conclusions, which is followed by a discussion of the limitations of the study. Recommendations for further research are discussed, as well as the clinical implications of this research.

7.2 Conclusions drawn from this study

- The subjective perceptions of HIV in the women's bodies: danger

For some of the women it was difficult to think about the HIV, with some of them claiming that they not previously thought about the HIV inside their bodies before. During the interviews, it became evident that some of the women struggled to engage with the concept of thinking about the HIV inside their bodies. However, for all of the women, the HI virus was connoted with concepts that represent danger, with this idea ranging from an act of attack, to an act of theft. From the drawings, the majority of the woman chose to use the colour red to represent HIV, with red connoting danger. For many of the woman a strong theme was that of HIV being a criminal, an entity that acts as a thief and steals. In addition to the HIV being viewed as a criminal, it was also felt to be attacking. This added another dimension to the idea of the virus being a thief, as well as that of something being stolen or taken away; HIV was depicted as violent and destructive. Thus, the women's subjective perception of the HIV in their bodies was markedly viewed as dangerous.

- The subjective experience of the ARVs in the women's bodies: security

The women of this study were all currently taking ARVs, and their attitudes towards the ARVs ranged from seeing the medication as good, seeing it as risky, to viewing it as both good and bad simultaneously. A theme that emerged surrounding the ARVs was them being connoted as a type of security force, that which combats the thieving and criminal action of the HI virus. Thus, in light of what was mentioned previously, many of the women felt the HIV to represent danger and the ARVs to represent life and safety. As demonstrated by the drawings, ARVs were

represented with yellow, green, and white, all colours that seem to connote light and wellbeing. However, a common theme that emerged from the interviews was also that of the ARVs being viewed as risky or dangerous. At times, the ARVs could be seen as good and helpful, but at other times they were seen to be something that was feared. It seems that the process of taking ARVs also appears on a spectrum, ranging from viewing the medication as all good or all bad. However, once a certain level of education and acceptance is achieved, the ARVs are able to be viewed as a whole object that is comprised of parts both beneficial and risky.

- The relationship between the individual, the HIV, and the ARVs in the body.

The relationship between the individual, the HIV, and the ARVs is a complex relationship. Following diagnosis, the relationship between the individual and the HI virus seemed to be predominantly associated with paranoid-schizoid functioning. This seemed to be necessary in order to manage the anxiety associated with diagnosis. However, after a certain amount of time and through the process of acceptance there seems to be a move towards the depressive position. In this new position, the individual is able to acknowledge that they are living with HIV, and that at times they may cope whilst at other times they feel unable to. It was also found that these factors influencing the shift along the continuum seemed to be influenced by the degree of stigma the woman had experienced, the amount of support she had received, and her ability to engage with the reality of HIV. The perception of the HIV in the body was determined upon where the person rested on what could be called a continuum. On the one end of the continuum exists a state whereby a person is unable to think about and unable to engage with the personal implications of the virus; in a state in which they appear to feel helpless. On the other end of the continuum exists a state whereby a person is able to think about the virus and feel they have accepted the reality of their diagnosis, and they are now coping. Thus, when first diagnosed, the women were only able to view the virus as dangerous and damaging. However, as the process of acceptance continues and as they move along the continuum, so the person is able to view the virus in both a positive and negative light. The toleration of both positive and negative attributes of the HIV implies a certain level of depressive functioning. The perception of the ARVs in the body was also dependent upon the level of processing the person had engaged with. It seemed that the process of taking ARVs also appeared on a spectrum, ranging from viewing the medication as all good or all bad. However, once a certain level of education and acceptance was

achieved, the ARVs were able to be viewed as more whole objects that are comprised of parts both beneficial and risky. One theme existed of the ARVs acting as facilitators between the person and the HIV. Thus, the ARVs perhaps acted as both a physical and emotional support system allowing for a person to regain their control, power, and strength. When an individual is able to view the ARVs as both good and risky, it could be posited that they have reached a depressive position.

7.3 Limitations of the study

Several limitations of this study exist:

- This study did not make use of a large sample. The number of participants in this study was quite low due to the limited scope of the study. Although, after six interviews similar themes began recurring and the decision was made to begin analysis. However, if more interviews had been conducted, perhaps more themes may have begun to emerge.
- The participants were all from the same shelter, thus the findings cannot be applied to the general population. The participants from the women's shelter were a group of socially vulnerable or marginalised black women. They were therefore not women who were self-sustaining or women that were functioning within their families and communities, and they were not representative of black HIV positive women in general.
- Since the women were all from the same shelter and are exposed to the same education and counselling regarding their HIV, this sometimes influenced the way in which they spoke of the HIV in their bodies. This may have influence the manner in which they engaged with the HIV/ARVs in their bodies.

7.4 Recommendations for further research

HIV is a well documented field of study, but whilst completing this study, several areas were found to be lacking in material and certain gaps were observed by the researcher.

- Firstly, Due to the restrictions on length for this master's thesis, certain areas were not fully explored in the literature review. This is in particular reference to the mind/body links regarding HIV, as well as the field of psychoneuroimmunology (PNI). Furthermore, it may have been useful to combine various theoretical approaches to the perception of HIV in one's body, but length restrictions prevented this. Thus, further research is recommended that include these areas.
- Secondly, a theme that emerged from this study was the male engendering of HIV by the women. This seems to be a complex and broad topic, so further research is recommended in exploring the role of gender in the personification of HIV. In addition, as the focus of this study was predominantly the subjective experience of HIV in the woman's body, it might be useful to explore the role of HIV in the man's body. Thus, further research is recommended exploring the internal worlds of the male and his subjective experience of HIV in his body.
- Thirdly, this study explored the triadic relationship between the individual, HIV, and the ARVs. Since ARVs are a relatively new addition to the treatment of HIV, there is very little existing literature regarding ARVs. Thus, future research is recommended in several spheres regarding ARVs. For example, literature is needed surrounding the attitudes felt towards ARVs, as well as research exploring the factors that influence the way an individual feels towards ARVs.
- Finally, the overall aim of this study was to explore the relationship that exists between HIV, the ARVs, and the individual. This is a complex relationship, and could be used to help understand the relationship that exists between an individual and other diseases or conditions i.e. cancer. Thus, future research is suggested in exploring these relationships and perhaps comparing them to the relationship that exists between a person and HIV.

7.5 Clinical Implications

From the findings of this study, as well as through the psychoanalytic interpretation of the findings, several clinical implications can be noted.

- Firstly, several of the women in the study claimed during their interviews that counselling helped them to cope with their positive diagnosis. However, it was further recommended that counselling is very much needed for the families. They claimed that when dealing with an HIV positive diagnosis, they were often confronted with a certain degree of stigma and ignorance in their families and that this was mainly due to a lack of knowledge. In addition, it is not only the individual diagnosed that is facing a difficult reality, but also their families who now possess an HIV positive family member. Thus, counselling and supportive therapy is recommended for the family.
- Secondly, one of the major findings of this study was the notion of thinking and intellectualisation being used as a defence against the anxiety of an HIV positive diagnosis and all that it entails. This could be useful to acknowledge and consider for clinicians when working with HIV positive patients. For example, it may be helpful to be aware of these defences and to target them when the patient is no longer using them adaptively.

7.6 Conclusion

This chapter provided a conclusive look at the broad findings of this study. It proposed recommendations for further research, and it also explored the limitations of this study. In sum, this study attempted to explore the subjective experience of HIV in the body, and discussed this experience via a psychoanalytic lens. However, this area proved to be quite dense and further research may be beneficial in exploring this further.

Chapter 8: References

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Chapter 9: Appendices

9.1 Interview Themes

Once the participants have completed the drawing of the HI virus in their body, the interviews will explore:

1. What does the virus look like inside your body?

This theme will revolve around the drawing that the participants will be asked to draw. The participants will be provided with paper and coloured pens. They will then be instructed to draw the virus within their bodies. Discussion will follow as to what they have drawn. Is it inside their body? What colour is it? This theme will allow for the participant to visually illustrate their perception of the virus in their body. As illustrated in Paula Luzzatto's study that explored the internal world of drug-abusers, drug abusers were required to use an art therapy technique called the 'self-image', and their projective pictures of self-object relations were analysed using the object relations theory (Luzzatto, 1987, p. 22).

2. Personification

Once the question, '*What are your thoughts, feelings, and perceptions of the virus within your body?*' has been asked, how the virus itself is personified will be explored. Questions may be asked around what words they would use to describe the virus? What personality the virus has? The questions that explore this theme will elicit information surrounding how the participants personify the virus itself, and what characteristics they attribute to it. This will allow for the researcher to explore whether the virus is seen in a negative or positive light, and whether these personifications are linked to external influences such as prior experience and/or stigma.

3. Beginning experiences

This theme will explore how the participants perceived the HIV following diagnosis? It is important to assess what the HIV was perceived like following diagnosis, so as to ascertain how the perceptions of the virus may have changed from diagnosis until present.

4. Has the relationship changed from beginning until present?

This theme will utilise the previous drawing. The participant will be asked as to whether the visual representation of the virus has changed since being diagnosed. If so, how? What does the virus now look like? They may also feel free to draw an additional diagram of the virus as it currently looks. These questions will allow for the researcher to explore whether the relationship changes as the virus progresses, and if so, what influences how the virus is perceived throughout this change.

5. How does it feel inside your body?

This theme will look at how the virus feels inside the participant's body.

At this point in the interview, the participant will be asked to add ARVs to their existing drawing. This amended drawing will then be explored.

6. Antiretroviral treatment

After the question '*What are your thoughts, feelings, and perceptions of the ARVs within your body?*' is asked, how the participant feels about the ARVs they are currently on will be explored? How does the participant personify the ARVs? Can they add the ARVs into their drawing of the virus? Where do they fit in? Are they seen as positive or negative? Why did they choose to take them? What considerations did they have? The world of antiretroviral treatment (ART) is limited in terms of research. It is interesting to note that one of the most prominent findings of the study conducted by Kremer *et al* (2006) is that mind-body beliefs and spiritual beliefs were mentioned by at least half of the participants of the study as reasons to either take or not to take ARVs. Due to the controversial nature of ARVs, this theme is important to address as it will explore how the personal and social stigma that surrounds ARVs is expressed in both a verbal and visual manner. Having discussed both the participants' attitudes to their HIV and ARVs, the question, '*What are the participants' thoughts, feelings, and perceptions of the relationship between themselves, the HI virus, and the ARV's?*' will be asked.

7. Disclosure

This theme will explore how the participant disclosed to family, friends, and colleagues about contracting the virus. Questions may be asked around what this process was like? Have they in fact disclosed to family and friends? What were the factors that may have

made this process difficult or stressful? This theme is important to explore as it will shed light on the notion of disclosure, which is often influenced by the stigma that surrounds HIV/AIDS. As cited in Rohleder and Gibson (2006), “Susan Sontag (1991) has argued that AIDS has emerged as a disease “whose charge of stigmatization, [and] whose capacity to create spoiled identity, is far greater” than that of other diseases” (p. 101).

In addition, the element of disclosure may indirectly influence how the virus is viewed. For example, if the persons HIV status is undisclosed, the virus may be viewed as secretive or in hiding. This theme may elicit information about the stigma that surrounds HIV. Thus, the question, *‘Are these relationships that you mention influenced by the way society views HIV/AIDS and ARVS? If so, how?’* will be asked and explored.

8. Previous relationships

Once the question, *‘Are these relationships influenced by any of your previous experiences in relationships?’* has been asked, the link between past and current relationships will be explored. This theme will look at whether the relationships with the HI virus or the ARV’s mimics or reflects any other relationships they may have or have had in the past. According to psychoanalytic theory, unresolved childhood conflict is reflected in later life, and as first proposed by Freud, adult association is influenced by our earliest forms of attachment in infancy. This process was elaborated further following Melanie Klein’s conception of projective identification, which refers to a process by which the infant, in phantasy, projects parts of ‘the self’ into objects (Nuttall, 2000). Thus, it is important to explore the current relationship that the participant has with the HIV/AIDS in their body and to compare this to previous relationships.

9. Mind-Body links

Having discussed the personification and nature of the relationship that exists between the person, the HIV, and the ARVs, the mind body links will be explored. Thus, the question, *‘Do you think that the way you feel about the virus in your body influences the course of the illness in any way? If so, how?’* will be asked. What is most relevant to this study is the notion that in African culture the Cartesian mind-body split is negated, and the mind and body are seen as closely interrelated (Eagle, 2005). Thus, for the purpose of this research it is important to keep in mind the cultural understandings of illness and

stigma that are associated with HIV/AIDS as these may influence the manner in which the HIV-positive individual relates to the virus in his/her body.

9.2 Participant Information Sheet



School of Human and Community Development

Private Bag 3, Wits 2050, Johannesburg, South Africa

Tel: (011) 717-4500 Fax: (011) 717-4559

Email: 018lucy@muse.wits.ac.za

Hello,

My name is Tiffany Gordon, and I am studying a Masters degree in Clinical Psychology at the University of the Witwatersrand. I would like your permission to conduct research as part of my degree. My area of focus is how someone living with HIV thinks and feels about the virus inside them. I want to know how you think the virus looks and how you feel about the virus in your body. I am also interested in how a person taking ARV medication feels and thinks about the ARVs. Due to the high rate of HIV/AIDS in South Africa, more research is needed that explores the relationship between the person living with HIV/AIDS and the virus itself. I would like to invite you to participate in this study.

If you decide to take part in my research, I will need one hour of your time to ask you a few questions. This interview will also be recorded if you agree, so that I can make sure that your point of view is clear. I will come and see you at the shelter at a time that is convenient for you, and we will sit in a private room and conduct the interview. The interview will look at how you feel and think about HIV, and also how you feel about ARV's. I will also ask you to draw the HIV in your body. This drawing does not have to be very good, I am more interested in how you think and feel about the HIV. There is no right answer; I am interested in what you have to say. Taking part of my study is voluntary and you may stop the interview at any time with no negative consequences. You will not receive any benefits or money for your participation. You may also choose not to answer any questions that you do not want to. There are no right or wrong answers in this study – what I am interested in is your experience.

When I write the report even though I will know your name, I will not use your name or any other information which might identify you in the report. The information collected will not be seen by anyone except myself and my supervisor. After the report is finished, data will be kept in password-protected files for a maximum of six years in case of future research, which only I have access to. After six years the information will be destroyed. General feedback will be given in the form of a letter to the shelter, but the finished research project will be available in the library of the University of Witwatersrand. If you are interested, you will be able to access the letter I have sent to the shelter.

This study is low risk, but if for any reason you feel upset or sad afterwards, you will be able to go for counselling free of charge at:

Emthonjeni Community Clinic (011 717 4513)

OR, you can call Lifeline (0861 322 322)

If you choose to participate in the study, please will you leave your name and contact details in the box I have provided. I will check the box regularly and will contact you directly to find a suitable time to conduct the interview. Alternatively I can be contacted telephonically at 0722467085 or via e-mail at tiffany.a.gordon@gmail.com.

The supervisor for this study is:

Dr. Katherine Bain
Clinical Psychologist/Lecturer
Discipline of Psychology
School of Human and Community Development
University of the Witwatersrand
011 717 4558
Katherine.bain@wits.ac.za.

Kind Regards

Tiffany Gordon

0722467085

9.3 Consent Form (interview)

I _____ consent to being interviewed by Tiffany Gordon for her study on “HIV as an internal object”. I understand that:

- Participation in this interview is voluntary.
- I may refuse to answer any questions I would prefer not to.
- I may withdraw from the study at any time.
- Direct quotes may be used in the report, however, no information that may identify me will be included in the research report, and my responses will remain confidential.
- There are no risks or benefits to participating in this study; however, if necessary I will be able to access free counselling.

Signed _____

Date _____

9.4 Consent Form (recording)

I _____ consent to my interview with Tiffany Gordon for her study on “HIV as an Internal Object” being tape-recorded. I understand that:

- The tapes and transcripts will not be seen or heard by any person in this organisation at any time, and will only be processed by the researcher.
- After the report is finished, data will be kept in password-protected files for a maximum of six years in case of future research, which only the researcher will have access to. All tape recordings will be destroyed after a maximum of six years after the research is complete.
- No identifying information will be used in the transcripts or the research report.

Signed _____

Date: _____

9.5 Letter from the Shelter

9.6 Ethics Clearance Certificate