

**INTIMACY, SEX AND SEXUALITY:  
THE EXPERIENCES OF VERTICALLY-INFECTED  
HIV-POSITIVE ADOLESCENTS.**

**A thesis submitted in partial fulfilment of the requirements for the degree of**

**Masters of Arts  
(Counselling Psychology)**

**of**

**RHODES UNIVERSITY**

**by**

**Lindsay Smail**

**December 2013**

## **Declaration**

I, the undersigned, hereby declare that this research project is, except where otherwise specified, my own work. It is submitted in partial completion of the degree of Master of Arts in Counselling Psychology at Rhodes University. It has not been submitted before for any other degree or examination at any other University.

---

Ms. Lindsay Smaill

## Acknowledgements

First and foremost I would like to thank the participants who agreed to be a part of this research. It was an enormous privilege to have been let into your lives. Without you this first look into the in-depth lived experience of being a vertically-infected HIV-positive adolescent would not have been possible. My thanks also go to the Raphael Centre for providing access to these participants.

I would like to thank my supervisor, Ms Ruby Patel, for her guidance and support during this research process. This is particularly for being willing to take on and fight so hard for a project that was considered code red for ethics. Your input has been invaluable and is greatly appreciated.

I would like to thank Sanelisiwe for so generously and sincerely volunteering her time to help with translation and Harry for similarly volunteering his skill to help with the editing of this research.

Financial assistance from the Rhodes University Prestigious Scholarship towards this research is hereby acknowledged. Opinions expressed and conclusions arrived at are those of the author and are not necessarily to be attributed to Rhodes University or the donor.

Lastly, I owe my deepest gratitude to my family and friends for their love and support during this research process. This is particularly to my fiancé, Will: your unfailing support been more valuable than words can say.

## **Abstract**

This research explores the lived experience of being a vertically or prenatally-infected HIV-positive adolescent. It looks specifically at how the participants experience intimacy, sex and sexuality. HIV/AIDS remains a global pandemic and vertically-infected adolescents are a growing new demographic. However, there is a poverty of research, and therefore interventions and support, for this demographic. This qualitative research conducted six individual, in-depth, semi-structured, psychoanalytic research interviews with three participants. The interviews were structured around projective drawings that the participants did in the course of each interview. The interviews were transcribed and analysed using psychodynamic object relations theory and organised through interpretative phenomenological analysis. Every effort was made to ensure that the research was conducted ethically and validly. The analysis found that the participants' experience of intimacy has resulted in a self that is constantly under threat. This in turn has negatively impacted on the participants' experience of sex and sexuality. The implication of this research is that more in-depth research needs to be done into this demographic so that better interventions and support may be offered.

## Contents page

1. Introduction	p. 1
1.1 HIV: The pandemic	p. 1
1.1.1 The changing HIV mortality and morbidity	p. 2
1.2 Vertically-infected HIV-positive adolescents	p. 3
1.3 Rationale	p. 4
1.4 Outline of chapters	p. 5
2. Literature review	p. 6
2.1 Introduction	p. 6
2.2 Contextualising HIV	p. 6
2.2.1 The politicisation of HIV/AIDS and ARVs	p. 6
2.2.2 HIV and stigma	p. 9
2.2.3 HIV, sex and sexuality	p. 11
2.2.4 HIV and constructs of masculinity, femininity and gender	p. 13
2.2.5 The self and HIV: The lived experience of being HIV-positive	p. 14
2.3 Adolescence	p. 17
2.3.1 Defining adolescence	p. 17
2.3.2 Sex, sexuality and sexual identity	p. 19
2.4 Vertically-infected HIV-positive adolescents	p. 22
2.4.1 HIV-positive adolescents: Vertically and horizontally infected	p. 22
2.4.2 Vertically-infected adolescents and the challenges that are faced	p. 26
2.5 Conclusion	p. 29
2.6 Research aim and question	p. 29
3. Theoretical underpinning	p. 30
3.1 Introduction	p. 30
3.2 Object relations theory	p. 31
3.2.1 The self: Internal reality, external reality and transitional space	p. 32
3.3 Internal reality: The unconscious mind and defences	p. 35
3.3.1 The unconscious	p. 35
3.3.2 Defences	p. 38

3.4 Klein's development of the self	p. 40
3.4.1 The paranoid-schizoid position	p. 40
3.4.2 The depressive position	p. 43
3.5 Sex and sexuality from a psychodynamic and object relations perspective	p. 47
3.6 Klein, object relations theory and vertically-infected HIV-positive adolescents	p. 50
3.7 Conclusion	p. 51
4. Methodology	p. 52
4.1 Introduction	p. 52
4.2 Research design	p. 52
4.3 Sample and sampling procedures	p. 52
4.4 Procedure	p. 54
4.5 Data collection	p. 56
4.5.1 Semi structured in-depth interviews	p. 56
4.5.2 Video recording interviews	p. 57
4.5.3 Psychoanalytic research interviews	p. 58
4.5.4 Projective techniques within the research context	p. 61
4.5.5 Interview 1	p. 61
4.5.6 Interview 2	p. 62
4.6 Data analysis	p. 63
4.7 Validity of research	p. 66
4.8 Ethical considerations	p. 68
4.9 Conclusion	p. 71
5. Findings and discussion	p. 72
5.1 Introduction	p. 72
5.2 The experience of intimacy:	
<i>"They give me hope even though I won't be alright"</i>	p. 72
5.2.1 Dominant attachment figures	p. 72
5.2.1.1 Early attachment figures	p. 74
5.2.1.2 Current attachment figures	p. 78



Appendix E: Guardian consent form	p. 146
Appendix F: Participant assent form	p. 147
Appendix G: Permission to video record	p. 148
Appendix H: Agreement with the translator	p. 149
Appendix I: Sihle's drawing for Interview 1	p. 150
Appendix J: Sihle's drawing for Interview 2	p. 151
Appendix K: Nicky's drawing for Interview 1	p. 152
Appendix L: Nicky's drawing for Interview 2	p. 153
Appendix M: Siphos drawing for Interview 1	p. 154
Appendix N: Siphos drawing for Interview 2	p. 155

## **List of tables**

Table 1: Participant demographics

p. 53

## **CHAPTER 1: Introduction**

This research project explores the lived experience of intimacy, sex and sexuality for three vertically-infected HIV-positive adolescents. These are adolescents who have been positive from birth, or soon after birth, and have survived into adolescence. For the purpose of this research intimacy is defined as the ability to form and maintain platonic and sexual relationships with others (Erikson, 1950). It is the experience of *being* with an other (Ivey, 1990; Winnicott, 1971). Sex and sexuality is defined as the subjective meanings that the participants attach to sex and sexuality and the negotiation of sexual identity (Auslander, Rosenthal, & Blythe, 2006; Epstein, 1991). It is hoped that this research will provide the beginnings of a basic, in-depth, subjective understanding of the vertically-infected HIV-positive adolescent demographic.

This research was conducted in the Grahamstown community, a semi-rural town in the Eastern Cape province of South Africa. Given the heavy disease burden of HIV in South Africa, as discussed below, it is likely that HIV is prevalent in the Grahamstown community.

### **1.1 HIV: The pandemic**

Human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) remain a global pandemic, with recent statistics indicating that approximately 33.4 million people are living with the virus (Li *et al*, 2010; UNAIDS, 2012c). With regards to children, from 2001 to 2006 just over half a million children were vertically infected globally per year (UNAIDS, 2012b). From 2007 there has been a steady decrease in new vertical infections down to 330 000 in 2011 (UNAIDS, 2012b). There are currently 3.3 million HIV infected, either vertically or horizontally, children globally (UNAIDS, 2012b).

UNAIDS (2012a) states that, regardless of their possible infection status, the world currently has “the largest generation of adolescents and young people ever” (p. 1). Therefore, the demographic is a significant one globally. UNICEF (2011) estimates that in 2009 5 million people between the ages of fifteen and twenty-four were HIV-positive. However, in 2010 “42% of new infections” occurred in people between the ages of fifteen and twenty-four (UNAIDS, 2012a, p. 1). Therefore, there is an increasing epidemiology of child and adolescent HIV rates (Ferrand *et al*, 2010).

Furthermore, according to UNAIDS (2012b) in 2011 Sub-Saharan Africa had 23.5 million people living with HIV. This is 69% of the global HIV burden, and so it is unsurprising that “Sub-Saharan Africa is the region most affected, with nearly 1 in every 20 adults living with HIV” (UNAIDS, 2012b, p. 2). Of the 42% of newly infected people between the ages of fifteen and twenty-four, almost 80% are in Sub-Saharan Africa (UNAIDS, 2012a). With regards to children, of the 3.3 million globally infected, 3.1 million are living in Sub-Saharan Africa (UNAIDS, 2012b). Southern Africa contains 2% of the world’s total population, and yet it carries one-third of the global HIV-positive population (Halperin & Epstein, 2007). It is no surprise then that HIV “is the leading cause of death in Southern Africa” (Ferrand *et al*, 2010, p. 428).

In 2008 South Africa had the highest HIV-positive population in the world (Richey, 2008) and this has not yet changed (Avert, 2012; UNAIDS, 2012e). The prevalence rates of HIV in South Africa are estimated at 5.6 million, or 17.3% of the general population, for 2011 (Avert, 2012). South Africa has 17% of the HIV disease burden, despite having only 0.7% of the total world population (South African Department of Health, 2011). This means that HIV is extremely prevalent in South Africa.

### 1.1.1 The changing HIV mortality and morbidity

UNAIDS (2012b) states that “half of all reductions in new HIV infections in the last two years have been among new born children” (p. 1). However, in 2011 globally there were still 330 000 newly infected children (UNAIDS, 2012b). In addition, only 28% of those children who should be on treatment are (UNAIDS, 2012b).

Sub-Saharan Africa in 2011 reduced its new infections by 25%, however “the region accounted for 72% of all new HIV infections worldwide” (UNAIDS, 2012e, p. 10). Significantly, “the number of AIDS-related deaths declined by nearly one-third in Sub-Saharan Africa between 2005 and 2011” (UNAIDS, 2012b, p. 1). This is directly linked to the fact that Sub-Saharan Africa has increased its treatment programme significantly in recent years (UNAIDS 2012e). This is so much so that “in 2011, an estimated 56% of people eligible for HIV treatment in Sub-Saharan Africa were receiving it – compared to a global average of 54%” (UNAIDS, 2012d, p. 2).

In Sub-Saharan Africa newly infected children have decreased by 24% from 2009 to 2011, however this is not significant enough given that “more than 90% of children who acquired HIV in 2011 live in Sub-Saharan Africa” (UNAIDS, 2012d, p. 2). Thus, Sub-Saharan Africa accounts for 300 000 of the world’s 330 000 new infected children (UNAIDS, 2012b).

South Africa, however, has reduced new infections by 41% from 2001 to 2011 (UNAIDS, 2012e). In addition, recently South Africa “has become home to the world’s biggest programme of HIV treatment, and the country’s life expectancy has gained five years” (Avert, 2012). In 2011 South Africa had “achieved more than 60% coverage of HIV treatment” (UNAIDS, 2012d, p. 2). This means that people are living longer with HIV in South Africa. Thus, HIV/AIDS is no longer a death sentence and is rather a chronic, manageable condition (Kelly, Freeman, Nkomo, & Ntlati, 2008).

There has been a decrease in child infection rates in South Africa by between 40% and 59% (UNAIDS, 2012d). This must be linked with the fact that in 2011 South Africa’s services to prevent mother-to-child transmission (PMTCT) covered more than 75% of the country (UNAIDS, 2012d). This has resulted in recent research finding that South Africa has a national rate of 3.5% of mother to child transmissions, and in the Eastern Cape specifically it is 4.7% (Health and Development Africa, 2012). Thus, South Africa’s newly vertically-infected population is decreasing.

### 1.2 Vertically-infected HIV-positive adolescents

With the pandemic proportions of HIV infection just described, it is no surprise that a significant number of children were, and continue to be, born HIV-positive. Although, there has been a decrease of new infections in this demographic, this does not remove the vast amount of vertical-infection that took place prior to medication being available in South Africa. It was previously thought that these children do not survive long; however, survival into adolescence is more common than originally thought (Mavedzenge et al, 2011). In addition, the introduction of highly active antiretroviral therapy (HAART) in public health clinics in South Africa since 2004 (Li *et al*, 2010) has in recent years ensured a longer life span for these children. Therefore, vertically-infected HIV-positive children are surviving

into adolescence and as such vertically-infected HIV-positive adolescents are a significant new demographic in HIV (Ferrand *et al*, 2010).

However, there is extremely limited research into the demographic. A search on the demographic reveals a domination of biomedical research. No research can be found examining the in-depth, subjective experience of being a vertically-infected HIV-positive adolescent. There is limited research from a psychological perspective (Fernet *et al*, 2007; Ferrand *et al*, 2010; Li *et al*, 2010), and even fewer HIV interventions for this demographic (Mavedzenge *et al*, 2011), and very limited South African based research. Therefore, the need for in-depth research into the lived experience of being a vertically-infected adolescent is clear.

### 1.3 Rationale

Following from the above, despite the significant number of vertically-infected HIV-positive adolescents, there is very little research, interventions and support for the demographic. From a theoretical perspective, adolescence is complicated for vertically-infected HIV-positive adolescents because of the impact that their HIV status has on intimacy, sex and sexuality.

Thus, the purpose of this research is to explore in-depth how vertically-infected HIV-positive adolescents experience intimacy, sex and sexuality. This is with regards to how adolescents integrate their lived subjective, social, intrapsychic, and interpersonal experiences in relation to these factors. This is fundamental because research into the experiences of this demographic will allow for better provision of services for these adolescents which in turn,

Is likely to lead to reduced possibilities of them infecting others, greater involvement in building awareness of the HIV epidemic, reduced morbidity because of access to health and support services, and greater ART compliance... reduction in stigma, thus leading to a reduction in fear about knowing and communicating HIV positive status, which also has prevention value. (Kelly, Freeman, Nkomo & Ntlati, 2008, p. 235)

#### 1.4 Outline of chapters

This research will aim to do this by firstly discussing the relevant literature pertaining to the demographic. Chapter two will discuss the context of HIV, the developmental stage of adolescence, HIV-positive adolescents generally, and lastly vertically-infected adolescents.

The third chapter outlines the theoretical underpinnings of this research. This research makes use of a psychodynamic, and more specifically object relations, framework to understand these adolescents. It focuses specifically on the work of Melanie Klein and her understanding of the oedipal complex, the paranoid-schizoid position, and the depressive position.

The next chapter makes explicit the methodology that was used for this research. It used a qualitative research design with non-probability, purposive and snowball sampling to sample three vertically-infected, adolescents. Data was collected, by means of video recording, during two semi-structured, in-depth, psychoanalytic research interviews per participant. These interviews were structured around a projective drawing that participants did at the beginning of each interview. The verbal and non-verbal information, together with the projective drawings, were then transcribed and analysed psychodynamically, in keeping with the object relations theoretical framework, and organised using Interpretive Phenomenological Analysis (IPA).

Lastly, chapter five outlines the findings from the analysis of the interviews. It discusses the findings in relation to the literature review and theoretical underpinnings of the research. The analysis identified three master themes: the participants' experience of intimacy, and therefore their view of the world and others; the participants' sense of self; and the experience and perception of sex and sexuality.

## **CHAPTER 2: Literature Review**

### **2.1 Introduction**

This chapter will discuss the relevant literature that already exists pertaining to the experience of intimacy, sex and sexuality for vertically-infected HIV-positive adolescents. It aims to contextualise HIV, explore the developmental stage of adolescence with a specific focus on sex and sexuality, discuss vertically-infected adolescents, and then lastly to bring together the challenges that exist for adolescents who have been HIV-positive since birth.

### **2.2 Contextualising HIV**

Bendelow (2009) states that “healthcare delivery and treatment can never be a purely scientific enterprise [because] human beings, whether delivering or receiving healthcare, are fundamentally subjective and value-laden beings” (p. 9). Therefore, disease is anything but merely biological.

Given how heavily HIV is stigmatised and politicised, HIV is possibly one of the most culturally and socially situated diseases in the world. Bardhan (2002) states that HIV “is as socially, symbolically, and communicatively constructed as it is a biomedical ‘reality’” (p. 221). It is therefore necessary to understand HIV within its context of politicisation, stigma, sex and sexuality, and gender constructs. This is because these factors necessarily impact on the lived experience of someone who knows themselves to be HIV-positive.

#### **2.2.1 The politicisation of HIV/AIDS and ARVs**

Treichler (1998, in Bardhan, 2002) argues that the broader context of dominant societal views and understandings of any phenomenon necessarily impact on, and construct, policy, which then inform local and individual understandings. Thus, the dominant global and governmental understandings of HIV and AIDS have necessarily influenced policy around HIV/AIDS and therefore how it has been treated. This, in turn, has impacted on millions of individual lives and lived experiences around the globe. This means that “the separation of the personal and the social reflects theoretical and political moments, rather than the experience and lived-reality of human life” (Hayes, 2012, p. 151). Thus, while HIV is a

disease experienced by the individual, the individual experience cannot be separated from the global and political policies that surround the disease. HIV is thus a highly politicised and constructed disease (MacGregor, 2009; Richey, 2008), such that the “political overtakes and orientates the personal experience” (Macgregor, 2009, p. 92).

McAllister (1992, in Bardhan, 2002) states that for most of the history of HIV/AIDS the dominant global understanding of the disease has been biomedical, and thus interventions and policies have been biomedically based. This is particularly the case in the West (Bardhan, 2002). However, this biomedical dominance ignores the fact that the “global political economy, race/ethnicity, gender, regionalism, nationalism, and politics will impact the way that the “roll-out” of antiretroviral drugs (ARVs) will take place in developing countries” (Richey, 2008, p.2). This initial lack of cultural sensitivity within global policy development makes it unsurprising that “there was much cultural resistance [to the biomedical model]... that took the form of governmental denial” around the globe (Bonacci, 1992, in Bardhan, 2002, p. 223). A primary example of this denial occurred within South Africa.

In 1999 Thabo Mbeki, the then President of South Africa, argued that ARVs are physically detrimental (Richey, 2008). In addition, Manto Mabalala Msimang, the Minister of Health at the time, refused to support ARVs as a viable way of managing HIV (Richey, 2008). Richey (2008) describes the power dynamics involved in South Africa in terms of how HIV was defined. This included struggles between Western and African knowledges, Mbeki, Msimang, the Western Cape, the Treatment and Action Campaign (TAC), and what is defined as scientific and what is not (Richey, 2008). This meant that South Africa was still in court debating the decision to roll out ARVs and PMTCT medication in 2002, just over ten years ago (Tang, 2010).

HIV was eventually defined as a scientific problem in South Africa (MacGregor, 2009; Richey, 2008), with the implication that it can be fixed through science and scientific knowledge (MacGregor, 2009). This made ARVs the solution to the problem of HIV/AIDS in South Africa. However, the power struggle in understanding and treating HIV has had a monumental impact on how the citizens of South Africa have understood, and conceived of, HIV and so how South Africans have sought to treat themselves (Richey, 2008). Thus, the politicisation of HIV has meant that “the pills cannot exist outside of their political context,

and the politics of contemporary health in South Africa cannot be considered without reference to ARVs” (Richey, 2008, p. 5).

Ultimately the power dynamics involved in defining HIV/AIDS in South Africa caused significant delays in the roll-out of medication and resulted in ARVs only becoming available in South African public clinics in 2004 (Li, *et al.*, 2010). This had devastating implications for those infected with HIV in South Africa (Chigwedere, Seage, Guskin, Lee, & Essex, 2008; Richey, 2008). South Africa’s delay in treatment resulted in more than 330 000 unnecessary deaths, in addition to 35 000 babies unnecessarily being born with HIV, for a total of 3.8 million person-years lost in South Africa between 2000 and 2005 alone (Chigwedere *et al.*, 2008). Thus, given the history, South Africa’s current ARV and PMTCT programme, as discussed in Chapter 1, is a huge gain for South Africa.

However, the benefit of treating HIV biomedically using ARVs, does not mean that HIV is merely a biological problem. HIV can be understood as “a developmental problem of poverty, a political problem of racism, and a gender problem of sexual inequality” (Richey, 2008, p. 20), to name a few. Richey (2008) argues that “now that HIV has been acknowledged to cause AIDS and ARVs have been agreed upon as part of its treatment, perhaps the other less proximate causes and non-pharmaceutical components of treatment can be taken up” (p. 21). This has been reflected in dominant global policies that have “begun to reflect wider social, cultural, economic, ethical, prevention, and education related issues and concerns” (Bardhan, 2002, p. 223). “AIDS/HIV is a polycultural phenomenon that involves the agendas, interactions, and interpretations of various groups/stakeholders” and as such a complex, multitudinal understanding needs to be taken into account when making policy decisions relating to the disease (Bardhan, 2002, p. 240).

The implication of South Africa’s denial of a biomedical understanding of HIV meant that until quite recently HIV infected mothers-to-be were passing HIV on to their infants either “during pregnancy, during the delivery or post-partum via breast-feeding” (Tang, 2010, p. 1). This means that prior to 2004 a vast number of infants were vertically-infected with HIV, as opposed to horizontally-infected via another transmission method. And now, with the accessibility of ARVs since 2004, a large number of these vertically-infected infants are surviving into adolescence. Thus, the new demographic of vertically-infected adolescents has

been heavily influenced by the politicisation of HIV and the nature of the roll-out of ARV and PMTCT medication in South Africa.

### 2.2.2 HIV and stigma

HIV is further complicated by the stigma that is attached to it. Stigma is defined as the process where “people who possess a characteristic defined as socially undesirable (such as HIV infection) acquire a ‘spoiled identity’, which then leads to social devaluation and discrimination” (Goffman, 1963 in Deacon, Uys, & Mohlahlane, 2009, p. 106). This serves the purpose of providing a false sense of security against the unwanted characteristic for the individuals and groups who are doing the stigmatising (Deacon *et al*, 2009).

Stigma is a socially constructed phenomenon. For example, Sontag (1991, in Rohleder & Gibson, 2006) states that society constructs metaphors “to interpret and understand the disease and those infected with the disease” (p. 26), which are then used to differentiate between those who are infected and those who are not. In this way stigma can be used as a form of social control in order to encourage ‘desirable’ behaviour and discourage ‘undesirable’ behaviour (Rohleder & Gibson, 2006). Additionally, stigma can be all encompassing as it can be directed towards the actual disease (HIV for example), people infected with the disease, and anyone and anything associated with the disease (Brown, BeLue, & Airhihenbuwa, 2010). In this manner stigma serves to discriminate against anything and anyone who is connected to HIV/AIDS.

Stigma can be instrumental, symbolic, felt, expressed, or perceived (Deacon *et al*, 2009). Instrumental stigma involves “fear of infection from casual transmission” (Deacon *et al*, 2009, p. 107). Symbolic stigma involves “moralistic shaming and blaming” (Deacon *et al*, 2009, p. 107). Felt stigma is stigma that has been believed and internalised by an individual (Deacon *et al*, 2009). Expressed stigma involves a change of behaviour for the worse as a result of stigmatising thoughts towards someone else (Deacon *et al*, 2009). Perceived stigma occurs when an individual makes “judgements about how much stigma they expect to experience” (Deacon *et al*, 2009, p. 107). Importantly, active discrimination is not necessary for stigma to be internalised and negatively impact on a person’s lived experience (Deacon *et al*, 2009).

In the case of HIV, “despite extensive public awareness campaigns, HIV remains a highly stigmatised disease that affects deviant ‘others’” (Rohleder & Gibson, 2006, p. 40). HIV has been “constructed as preventable or controllable” such that “people are blamed for their own infection” (Deacon *et al*, 2009, p. 107), and so suddenly infection becomes a moral, rather than a biological, matter. Sontag (1991, in Rohleder & Gibson, 2006) states that society’s metaphors surrounding HIV and AIDS include “HIV as death, as crime; as war; as otherness; as horror; and the HIV sufferer as villain” (p. 26). In addition HIV is seen as “a plague, evil, and sinful” (Sontag, 1991, in Rohleder & Gibson, 2006, p. 26). Hayes (2012) states that “AIDS encapsulates sex, promiscuity, drugs, morality and death” (p. 150). Thus, it is clear that stigma has made HIV the disease, those infected with HIV, and those associated with HIV extremely undesirable.

Brown *et al* (2010) state that “HIV/AIDS stigma is a key factor that contributes to the difficulties in controlling the epidemic” (p. 442). This is in terms of both preventing further infection and caring for those who are already infected (Rohleder & Gibson, 2006). Research shows that both “experienced stigma and perceived stigma [are] related to inconsistent condom use, fear of disclosure, depression or anxiety and lack of self-efficacy or confidence” (Maughan-Brown, 2007, in Deacon *et al*, 2009, p. 110). This then impacts negatively on infection rates, support access and treatment. For example, if someone is unwilling to disclose their status they will be “unable to find social and family support, thereby aggravating their sense of helplessness and loneliness” (Hackl, Somlai, Kelly, & Kalichman, 1997, in Rohleder & Gibson, 2006, p. 27). Thus, stigma “reduces the impact of prevention programmes, inhibits treatment take-up and adherence, exacerbates the psycho-social effects of HIV-infection and reduces the quality of life of people living with HIV and AIDS” (Deacon *et al*, 2009, p. 105). It is unsurprising then that stigma has been identified as “a risk factor in the psycho-social adjustment of children affected by HIV and AIDS” (Deacon *et al*, 2009, p. 110). HIV-related stigma is also heavily involved in perpetuating already existing inequalities around class, race, gender, and sexuality (Parker & Aggleton, 2003, in Rohleder & Gibson, 2006), which are in turn used to further blame and ‘other’ people who are HIV-positive.

Thus, HIV-related stigma is deeply problematic and plays a crucial role in determining the lived experience of people who are HIV-positive. This is so much so that when someone is diagnosed, HIV-related stigma becomes a primary concern (Rohleder & Gibson, 2006). Thus,

it is highly likely that HIV-related stigma will have an impact on how the participants in this research experience intimacy, sex and sexuality.

### 2.2.3 HIV, sex, and sexuality

The prevalence and impact of HIV/AIDS has made the issue of sex a primary concern in South Africa. Hayes (2012) states that “unless one gets to the basis of the formation of sexual morality... there is little prospect of making AIDS a problem which affects us all” (p. 151). This means that addressing constructs of sexuality in relation to HIV/AIDS might be the key to reducing stigma and the othering of HIV. However, having said that, it is important not to reduce HIV/AIDS to simply a problem of sex. Hayes (2012) states:

HIV/AIDS is not just about sex, it is much more comprehensively about *relationships*, about various forms of intimacy and not only sexual intimacy, about the division between affection and sensuality, about who lives and who dies, about dignity and respect, and about what it means to be human in this precarious new century. (p. 160)

Research shows that the number of partners does not influence HIV transmission rates, so much as multiple concurrent relationships (Halperin & Epstein, 2007). Research found that when comparing serial monogamy with long-term concurrent relationships “HIV transmission was much more rapid with long-term concurrency – and the resulting epidemic was some 20 times greater” (Halperin & Epstein, 2007, p. 20). This is because the HIV virus is much more infectious during the first three to four weeks of infection (Halperin & Epstein, 2007). This means that “as soon as one person in a network of concurrent relationships contracts HIV, everyone else in the network is placed at risk” (Halperin & Epstein, 2007, p. 20). Halperin & Epstein (2007) state though that “large-scale heterosexual concurrency networks can only emerge if a significant proportion of women are also engaging in multiple, longer-term relationships” (p. 21), which is, unfortunately a significant culture within Southern Africa (Halperin & Epstein, 2007).

Alternatively, within serial monogamous relationships, if one partner becomes infected they probably will have become less infectious by the time that a new partner is established. In other words, “serial monogamy traps the virus within a single relationship for months or

years, so when a new partner is engaged the acute infection period of unusually high HIV infectivity has usually passed” (Halperin & Epstein, 2007, p. 20).

It is therefore a state of concern that “the modern trend is towards greater sexual exchange, multiple sexual partnering and partner-switching” (Ankomah & Ford, 1994, p. 124). People’s knowledge around safe sex practices and reducing their risk of infection does not translate into their behaviour (Hayes, 2012). This means that sexual behaviour is not completely rational. In addition, the fact that sex occurs so extensively and constantly, and yet in private, makes it very difficult to change and challenge sexual behaviour (Ankomah & Ford, 1994), especially a behaviour that is so deeply embedded within a culture.

Hayes (2012) argues that humans are inherently sexual and driven by sexual desire. However, sex is also unavoidably traumatic (McDougall, 1995, in Hayes, 2012). Sex is made even more complicated by that fact that “sex is not just one thing, nor does it have a stable meaning across culture and time” (Hayes, 2012, p. 155). Hayes (2012) further states that “more so than any other biological, natural or bodily dimension... sex is inherently inscribed in a moral universe” (p. 153).

So it is unsurprising that the issue of HIV, sex and sexuality has resulted in the development of significant surrounding discourses, which in turn have direct implications for the role of stigma in a person’s life. Hayes (2012) argues that discourses tend to centre on “condom and sanitised notions of safe sex” and tend to ignore “sex, sexual practices, sexual enjoyment, sexual taboos and myths, and the broad range of psychosexual relationships among people, particularly *young* people” (p. 153).

Thus, “HIV infection is commonly associated in shaming and blaming discourse with sex and specifically promiscuity” (Deacon *et al*, 2009, p. 110). This means that some people are seen as “‘innocent victims’ and others are seen as more blameworthy, often depending on their age, gender, class or the mode of infection” (Deacon *et al*, 2009, p. 110). In other words, sex has become the bad and dirty means through which people acquire the punishment of HIV-infection. For example, people who are vertically-infected are seen as innocents who did nothing wrong to become infected and as such are victims, and those who acquire the disease horizontally through sex are perceived as blameworthy and responsible.

#### 2.2.4 HIV and constructs of masculinity, femininity and gender

Pivotal to sex and sexuality is the role that gender and gender inequality plays in relation to HIV. South Africa is pervasively a patriarchal society (Jewkes, 2009) with men, or rather hegemonic masculinity, perceived as dominant and women as subordinate. In relation to HIV this is problematic in two ways: firstly, it places both sexes at increased risk of contracting HIV; and secondly, it reduces ways of coping once an individual, but particularly a man, has been diagnosed. Thus, “the role of gender, sex and power needs to be examined” in relation to HIV and AIDS (Walker, Reid, & Cornell, 2004, in Rohleder & Gibson, 2006). This idea is supported by Lindegger and Quayle (2009, p. 41) who state that “it is increasingly apparent that the social construction of masculinity plays a major role in putting women (and men) at risk of HIV infection” (p. 27).

Gender inequality is a long standing problem. Delius and Glaser (2002, in Jewkes, 2009) state that “the emphasis on masculinity in power and control over women has been part of processes of socialisation of men throughout the period for which historical evidence exists” (p. 34). Jewkes (2009) argues that the inferiority of women within such a patriarchal society has impacted on their risk to HIV-infection. This subordination has been further compounded by “the apartheid legacy of poverty, poor educational attainment, lack of opportunities and high youth unemployment” (Jewkes, 2009, p. 37). This has inevitably influenced “women’s perceptions of their lives, relationships and sexuality” (Jewkes, 2009, p. 37).

Rohleder & Gibson (2006) state that “in South Africa black women generally occupy the lowest rungs on the hierarchy of social, economic and political power” (p. 27). It can be no coincidence that black women also carry most of the HIV disease burden in South Africa (Jewkes, 2009). Although it cannot be ignored that women are biologically more susceptible to HIV infection, the research into male and female infection rates points to the idea that “the epidemic in women is disproportionately driven by the behaviour of a relatively small group of HIV-infected older men who have a large number of partners” (Jewkes, 2009, p. 27-28). Women’s perceived inferiority places them at a disadvantage in negotiating sex and condom usage (Green, 1994; Jewkes, 2009). In addition, “gender differences also play a role in the construction of promiscuity and deviance; many sexual partners are a testament to a man’s manhood, whereas women with many sexual partners are regarded as dirty” (Rohleder & Gibson, 2006, p. 27). Furthermore, “violent and controlling behaviours of men are associated

with HIV risk in women” (Jewkes, 2009, p. 35). Thus, a correlation seems to exist in terms of behaviour, gender roles, and power dynamics to further worsen women’s risk to HIV.

However, gender inequality not only results in the disempowerment, disadvantage, and increased risk of HIV-infection for women, but for men as well. It is important to see this as indicative of the wider problem of how masculinity is constructed within South Africa. This is because the “powerful and unattainable demands” (Lindegger & Quayle, 2009, p. 47) of the dominant construction of masculinity, hegemonic masculinity, both increase men’s risk for HIV-infection and reduce their space for vulnerability and coping.

Unfortunately, hegemonic constructions of masculinity are often in line with exactly those behaviours that are risky in terms of contracting HIV (Lindegger & Quayle, 2009). These include being sexually active, risk-taking, having an “uncontrollable sex drive”, having multiple partners, partaking in transactional sex, forcing sex, and using drugs and alcohol (Jewkes, 2009; Lindegger & Quayle, 2009, p. 43). Another implication of hegemonic masculinity is that sex cannot be thought of as an intimate, emotional relationship, but rather as an act through which men prove their manhood (Lindegger & Quayle, 2009).

However, while hegemonic masculinities demand “physical and emotional toughness”, they in fact “result in fundamentally vulnerable positions for individual men and, simultaneously, [obstruct] acknowledgement of emotional vulnerability” (Segal, 2006, in Lindegger & Quayle, 2009, p. 42). South Africa’s construction of masculinity thus leaves very little room for anything other than hegemonic constructs of masculinity, such as women being in power or men being vulnerable and emotionally connected to themselves and others.

Thus, South Africa’s “particular forms of sexual repression, the problematic masculinist notions of male gender identity, and the persistence of patriarchal relations” (Hayes, 2012, p. 154) are adding to South Africa’s HIV disease burden and limiting both men’s and women’s means of coping.

#### 2.2.5 The self and HIV: The lived experience of being HIV-positive

Very important to the lived experience of being HIV positive is the meaning attached to HIV and being HIV-positive. This is because it impacts on an individual’s sense of self and

therefore how they experience intimacy, sex and sexuality. The meaning attached to HIV and being HIV-positive is necessarily impacted on by the politicisation, ARVs, stigma, and constructs of sex, sexuality and gender surrounding HIV and AIDS. Kelly *et al* (2008) state that:

To a large extent the meaning of HIV/AIDS was often not based on experience of the responses of other or experience of the effects of HIV/AIDS, but on the prevailing image of HIV/AIDS as a death sentence and the expectation of experiencing stigma and isolation during a slow and inexorable process of deterioration and disease. (p. 231)

There seem to be “three domains of meaning” that anyone who is HIV positive has to negotiate: “having a chronic and possibly fatal medical condition; being infective to others; and the realities of perceptions of others and society about what it means to be HIV positive” (Kelly *et al*, 2008, p. 231). This is supported by Rohleder and Gibson (2006) who identified all three concerns in their research. Rohleder and Gibson (2006) found that “receiving an HIV-positive diagnosis caused much distress, as thoughts of death came immediately to mind”, there were significant concerns around the self being dangerous in terms of possibly infecting others, but that their participants’ core pain was negotiating stigma and others’ perceptions of them and HIV (p. 32-34).

Green (1994) particularly supports the idea of how HIV negatively impacts an individual’s sexuality in terms of infecting others. Green (1994) states that “people diagnosed with HIV... have to reassert their sexual identities and re-establish sexual relationships within a hostile and frightening environment related to their potential to infect others” (p. 136). Thus, people who are HIV-positive often experience guilt and fear, particularly fear of rejection if they disclose their status, in relation to their sexual identity. Green’s (1994) research found three types of responses in renegotiating sexuality after becoming HIV-positive:

The first is the path of celibacy, the second is that of denial of the possibility of infecting others and failure to modify behaviour, and the third is the path of behaviour modification which enables a sex life to continue while placing HIV-negative partners at minimal risk. (p. 144)

However, HIV impacts negatively on a person's ability to be intimate not only sexually, but also in plutonic relationships with others (Smiley, 2004). This is because "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 exchanges of any kind" (Smiley, 2004, p. 252).

MacGregor (2009) describes how HIV-positive people experience fear as a result of "witnessing others dying ugly, emaciated deaths and the uncertainties associated with the drugs with respect to both toxicity and resistance" (p. 93). In addition, MacGregor (2009) describes how body maps done by HIV-positive women "evoke the sense of vulnerability and the loss of control of the corporeal boundaries of the body" (p. 93). In other words, the experience of living in an HIV-positive body is to experience the loss of boundaries, and the related sense of safeness, as the body starts to develop sores and disintegrate. This is because "the unbounded body of the ill is a body out of the control of medicine" (MacGregor, 2009, p. 93) and self. This is supported by Smiley (2004) who states that "there is acute emotional distress in living day-to-day with a life-threatening illness that induces bodily disintegration of all kinds" (p. 252).

Rohleder and Gibson's (2006) research showed that although prior to being diagnosed participants had identified HIV as something that happens to others, once they became aware of their status the participants internalised society's negative perceptions and discourses of HIV as part of their identity. This meant that the participants internalised an idea of themselves as "dirty, dangerous and contagious" (Rohleder & Gibson, 2006, p. 33). Rohleder and Gibson (2006) argue that this can occur because "they would already have had some prior investment in these discourses in order to place themselves outside 'those groups at risk'" (p. 40). Therefore, people who are HIV-positive tend to adopt a "spoiled identity" (Rohleder & Gibson, 2006, p. 40) and as such "the virus can radically transform one's sense of self and of the self in relation to others" (Smiley, 2004, p. 252). As a result, it is traumatic to live with HIV (Smiley, 2004).

Unsurprisingly, then, research has consistently found high rates of mental health problems in HIV positive populations (Kelly *et al*, 2008; Smiley, 2004). This is either as a direct complication of the disease or as a result of the stress of living with HIV (Smiley, 2004). The most common mental disorders seem to be depression and alcohol abuse (Kelly *et al*, 2008). However, it was found that the "presence of (any) mental disorder was significantly

associated with the clinical stage of progression of HIV/AIDS” such that the further developed HIV/AIDS is, the higher the chances of the presence of a mental disorder (Kelly *et al*, 2008, p. 226). In addition, the likelihood of a mental disorder increases with the experience of losing someone close due to HIV/AIDS, but not due to other causes of death (Kelly *et al*, 2008). Kelly *et al* (2008) argue that there is “a complex relationship of mutual causality” between unemployment, HIV/AIDS and mental health problems (p. 227).

However, although research on HIV has increased over the last few decades, Lawson (2000, in MacGregor, 2009) states that academia has paid little attention to the lived experience of having a diseased body. This is surprising given that, “in the context of AIDS, it is this experiential reality that has to be confronted in the social experience and negotiation of stigma” (MacGregor, 2009, p. 93), and therefore the uptake of treatment and safer sex practices. This is because research shows that “psychological, psychosocial and psychiatric factors play a significant role in how well people comply with antiretroviral treatment” (Kelly *et al*, 2008, p. 232).

Thus, “the experience of being HIV positive is a complex process and positive outcomes are not assured” (Kelly *et al*, 2008, p. 232). This is because “a positive outcome requires social support, or at least perceived social support, and acceptance as well as qualities of resilience and confidence” (Kelly *et al*, 2008, p. 232). Kelly *et al* (2008) state that support programmes should include a space to discuss disclosure, stigma, romantic relationships, being able to infect others, and information on managing HIV. Green (1994) argues that HIV-positive people should be given “sex counselling to increase their ability to practice and enjoy safer sex” (p. 145). However, this support is difficult to find (Kelly *et al*, 2008), unsurprisingly given how little research has been done into the lived experience of being HIV positive.

## 2.3 Adolescence

### 2.3.1 Defining adolescence

Adolescence refers to a developmental stage that is emotional, social and sexual (Herbert, 1998). Puberty brings about sexual maturity, ending childhood and beginning adulthood (Erikson, 1950). Leading theorists broadly define adolescence as “the transitional stage of autonomy seeking, identity exploration and emotional stability” (Burrow & Hill, 2011, p.

1197). It is generally “defined as the period between 10 and 20 and typically is divided into three phases: early (ages 10 to 14), middle (ages 15 to 17), and late (ages 18 to 20)” (Auslander *et al*, 2006, p. 694).

Bateman and Holmes (1995) state that during adolescence the “acquisition of cognitive and motor skills, and the capacity to go beyond the family into a world of peer relationships, are the predominant developmental tasks” (p. 70). This means that there are a multitude of changes that occur during adolescence, with adolescents starting to think more about themselves and their futures, changing family dynamics with peer relationships becoming more important, and changes in their self-image as their bodies develop (Bukatko & Daehler, 2004). In other words, adolescents are set the task of developing their ego identities, which involves the sense that the way they view themselves internally is the same as the way that others perceive them (Erikson, 1950).

As children become adolescents, their cognitive abilities become increasingly complex (Bukatko & Daehler, 2004). This means that adolescents are capable of emotions that are more complicated. In addition, “the adolescent no longer relies on the parent to regulate and modulate [their] bodily affective states, but has to undertake this task for [him or herself]” (Bateman & Holmes, 1995, p. 70). Depression and suicide are a considerable risk during adolescence. The National Institute of Mental Health (2002, in Bukatko & Daehler, 2004) states that “suicide is now the third leading cause of death among fifteen to twenty-four-year-olds, and the fourth leading cause of death among children ages ten to fourteen” (p. 396). Adolescence thus refers not so much to puberty and the changing body, but to the psychological developments that occur (Herbert, 1998).

According to Erikson (1950), adolescents are negotiating the task of either establishing an identity or experiencing role confusion, and approaching or starting to engage with either establishing an intimate relationship or being alone. This means that they are simultaneously negotiating the “tasks of separation from [their] family of origin, and preparing [themselves] for the intimacies of [their] family of generation” (Bateman & Holmes, 1995, p. 70).

The task of identity formation means that adolescents are concerned with how to integrate the different parts of themselves from childhood, the roles they play during adolescence, and what they want for their futures, into a coherent identity (Erikson, 1950). In other words,

adolescents are set the task of starting to create their own lives as they would like them to be (Bateman & Holmes, 1995). Intimately connected to this identity formation is how adolescents experience and perceive their bodies (Bateman & Holmes, 1995).

Bateman and Holmes (1995) state that both a reactive identity based on what the adolescent does not want to be and an overly compliant identity based on parental ideals can “conceal an inner sense of emptiness and a lack of connection” (p. 70). Therefore, the process of identity formation is an extremely important one. This is supported by research that shows that “establishing an identity... [is] developmentally adaptive during adolescence and emerging adulthood” (Burrow & Hill, 2011, p. 1197). There are a few theories on how exactly this occurs but they all state that adolescents form their identities through actively exploring different identities and then committing to them slowly over time (Erikson, 1950; Marcia, 1966; & Waterman, 1993, all in Burrow & Hill, 2011). If this does not happen, role confusion is experienced (Erikson, 1950). This is problematic because the resolution of identity has direct links to the developmental challenges of intimacy (Erikson, 1950).

The developmental task of intimacy means that “adolescents are faced with many developmental tasks related to sexuality, such as forming romantic relationships and developing their sexual identities” (Auslander *et al*, 2006, p. 701). Sexual identity is “how a person defines himself or herself in terms of sexual attractions, thoughts, fantasies, behaviours, and life style” and is influenced by an individual’s sex, gender, sex roles, and sexual orientation (Auslander *et al*, 2006, p. 695).

### 2.3.2 Sex, sexuality and sexual identity

Epstein (1991) defines sexual identity as “all the ways in which people operate in a socially-defined sexual sphere, see themselves as sexual beings, and achieve a greater or lesser degree of consistency in their sexual relational experiences” (p. 827). Implicit in understandings of sexual identity is the assumption that people are sexual. As such there is extensive social pressure to be sexually active, or at the very least, conceive of oneself as having sexual desire (Bogaert, 2012). Epstein (1991) suggests that sexual identity includes: “sexual preference or orientation”, which is the kinds of people individuals are attracted to; “erotic role identity”, which is what an individual likes to do; and “the conscious identification of self with social sexual typologies (or the failure to do so)”, such as labelling oneself as ‘straight’ or ‘bisexual’

(p. 828). Deeply entwined in an individual's sexual identity is their gender identity and constructs of femininity and masculinity (Epstein, 1991). Epstein (1991) maintains that an individual's sexual identity is a fundamental part of their overall sense of self.

Despite the importance of the development of sexual identity, research on the topic, particularly heterosexual identity, is limited (Eliason, 1995; Morgan, 2012; Striepe & Tolman, 2003; Worthington, Savoy, Dillon, & Vernaglia, 2002; Yarhouse & Tan, 2004). In the face of what psychology knows about adolescent development as a stage in which individuals "[feel] like they do not fit in and [struggle] to make sense of who they are" it seems that heterosexual identity development has been assumed to not be part of this confusing process (Striepe & Tolman, 2003, p. 529). Research has found that this is not the case, such that there is a need for normalising sexual identity exploration for adolescents and for acknowledging in-group differences in heterosexuals (Eliason, 1995; Morgan, 2012; Striepe & Tolman, 2003).

Yarhouse and Tolman (2004) state that there have been three major contributors to theory on heterosexual identity formation: Eliason, Mohr, and Worthington *et al.* Eliason (1995) conducted research with twenty-six self-identified heterosexual students. She identified seven themes: "never thought about sexual identity; outside forces made me heterosexual; gender socialisation made me heterosexual; heterosexuality is inborn, fixed; heterosexuality is a choice; there are no viable alternatives; [and] religion was a factor" (Eliason, 1995, p. 826). Thus, heterosexual sexual identity formation is neither homogenous nor simple, and as such fits with the theory on general identity formation (Marcia, 1987, in Eliason, 1995).

Mohr (2002) makes the case that "heterosexual identity is different from heterosexuality itself, however, because it signifies *understanding* that individuals have of their sexual orientation rather than the sexual orientation itself" (p. 536). In other words, "whereas heterosexuality refers to opposite-sex attractions, fantasies, and behaviour, heterosexual identity refers to ways that people interpret these attractions, fantasies and behaviours" (Mohr, 2002, p. 536).

Mohr (2002) states that heterosexual identity is socially constructed. Therefore, it is argued here that this is the case for all forms of sexual identity. This means that sexual identity is not an innate fact that exists in the world but rather a way of thinking about sexuality that comes

about as a result of a myriad of interplaying factors. This is in line with Worthington *et al* (2002) who state that in addition to heterosexual identity development, the biopsychosocial influences on sexual identity development are also often not considered. These include biological processes, which influence “sexual health, development, desire, behaviour, reproduction, and orientation” (Jones, Shainberg, & Byer, 1978; Tortora & Anagnostakos, 1981, both in Worthington *et al*, 2002, p. 502); the microsocial context, which refers to the people that individuals relate directly and often with from whom they often learn sexual values and norms (Worthington *et al*, 2002); gender norms and socialisation, which are the social and cultural ideas around how each gender should be and behave (Worthington *et al*, 2002); culture, which defines and gives meaning to sex thus making “vast variations in sexual practices, values, and meanings across cultures” (Worthington *et al*, 2002, p. 506); religious orientation, which often prescribes certain sexual morals and values and so impacts on the level of exploration and commitment that an individual may go through during their sexual development (Worthington *et al*, 2002); and systemic homonegativity, sexual prejudice, and privilege, which refers to the fact that the dominant norm in society is heterosexuality which thus creates power dynamics (Worthington *et al*, 2002). It can be assumed that all these factors are extremely important in the development of vertically-infected HIV-positive adolescents’ sexual identities.

Thus, Worthington *et al* (2002) suggest a “multidimensional model of heterosexual identity development” (p. 509). Morgan’s (2012) research showed support for this model.

Worthington *et al* (2002) suggest that heterosexual identity occurs within the biopsychosocial context and consists of both individual sexual identity and social sexual identity. Mohr (2002) supports this idea that sexuality has “both personal and public components” (p. 536).

Individual sexual identity processes include “one’s sexual needs, values, sexual orientation and preferences for activities, partner characteristics, and modes of sexual expression” (Worthington *et al*, 2002, p. 510). Social sexual identity processes include “the recognition of oneself as a member of a group of individuals with similar sexual identities... and attitudes towards sexual minorities” (Worthington *et al*, 2002, p. 510).

Social sexual identity is so important because of the dominance or assumption of heterosexuality in society such that “sexual orientation identification often has profound implications for individuals’ status” (Fassinger, 1991, in Mohr, 2002, p. 536-537). Eliason (1995) states that “masculinity and heterosexuality are entwined in the socialisation process

in a much more direct and powerful way than femininity is tied to sexual identity” (p. 829). In other words, society equates masculinity to heterosexuality (Yarhouse & Tan, 2004).

Sex and sexuality, especially when talking about children or adolescents, is a highly contested, emotive subject (Burman, 2008). Key to sex and sexuality is that they cannot be understood “outside of the prevailing structures of regulation and surveillance that produce them” (Burman, 2008, p. 138). The dominant discourse surrounding sex and sexuality with regards to children and adolescents makes it something that happens *to* them as opposed to something that they *are* or *have* (Burman, 2008). Freud (1905) states that it is unfortunate that “the existence of the sexual instinct in childhood has been denied and that the sexual manifestations not infrequently to be observed in children have been described as irregularities” (p. 232). This immediately disempowers children and adolescents and has a negative impact on sex education and teenage pregnancy interventions (Burman, 2008). Therefore, Burman (2008) suggests that “there is a need to reconceptualise access to sexual knowledge, to move away from notions of complicity to focus on power, including crucially the power relations that construct the ways we view children” (p. 117-118).

#### 2.4 Vertically-infected HIV-positive adolescents

As discussed, significant in HIV is the new demographic of vertically-infected HIV-positive adolescents (Ferrand *et al*, 2010). Ferrand *et al* (2010) state that “there has been considerable emphasis on the prevention of HIV infection in adolescents, but much less on the care of those already infected” (p. 430). Therefore, there is very little psychologically based research into the demographic and so little is known about the in-depth lived experience of being a vertically-infected HIV-positive adolescent.

##### 2.4.1 HIV-positive adolescents: vertically and horizontally-infected

As discussed in Chapter 1, adolescents are a significant proportion of the global HIV-positive population. The demographic can be divided into two groups: vertically-infected adolescents and horizontally-infected adolescents. As stated previously, vertically or perinatally-infected adolescents are those adolescents who have been infected since, or soon after, birth and as such have lived their entire lives as HIV-positive. Alternatively, horizontally or

behaviourally-infected adolescents are those adolescents who have been infected later on in life, usually through sexual transmission.

Research shows that vertically acquired HIV has a negative developmental impact on children and adolescents (Li *et al*, 2010; Wachsler-Felder & Golden, 2002). The earlier that HIV is contracted the more likely it is to impact on development, thus leaving vertically-infected children more negatively impacted on than horizontally-infected children or adolescents.

One of the major developmental tasks that adolescents have to negotiate is that of sex, sexuality and intimacy (see 2.3). Typically, romantic relationships are challenging because “sexuality is about a lot more than having sex. It is about the social rules, economic structures, political battles and religious ideologies that surround physical expression of intimacy and the relationships within which such intimacy takes place” (Cornwall, Corrêa, & Jolly, 2008, p. 5). This is especially during adolescence when “the mixed peer group becomes predominant, and forms a background to the development of a personal and sexual identity” (Copley, 1993, p.83). In other words, romantic relationships bring up “questions of identity, sexual expression, pleasure, and risk” (Cornwall *et al.*, 2008, p. 8). Therefore, romance, sex, and sexuality must be that much more challenging for HIV-infected adolescents because of its direct link with HIV as discussed previously (see 2.2.3).

Wiener and Lyon (2006, in Fernet *et al*, 2007) suggest that although research is limited it seems that vertically-infected “HIV-positive adolescents... become sexually active later than their non-infected peers” (p. 102). This could be due to the delay in the onset of puberty in these adolescents (Fernet *et al*, 2007), but it also seems highly likely that this is linked to the conflicted space that sex necessarily posits for these adolescents. Fernet *et al* (2007) found:

Youth living with HIV since birth showed emerging interest in sexuality, some were sexually active, and most, whether active or not, were conscious of the need to prevent HIV transmission, aware of the interpersonal responsibility involved in doing so, and concerned about the rejection that might come if they were to disclose their HIV status to a partner. (p. 108)

This is similar to the findings from research with horizontally-infected adolescents (Murphy *et al*, 2001; Rotheram-Borus *et al.*, 2001; Vermund *et al*, 2001; Ciener & Lyon, 2006, all in Fernet *et al*, 2007). This concern about being rejected may be so great that Kang, Mellins, Yiu Kee Ng, Robinson, and Abrams (2008) state that some adolescents “avoid romantic relationships entirely because of the inevitability and necessity of disclosure, and the possibility of risky sexual activity that will result in HIV or STI transmission” (p. 232). However, there are some differences in sexual behaviour patterns between vertically-infected and horizontally-infected HIV-positive adolescents in that research seems to suggest that vertically-infected adolescents are more likely to use a condom both in relation to ever having used a condom and in consistent condom use (Fernet *et al*, 2007).

Ebersöhn and Eloff (2002) state that “HIV/AIDS triggers multiple anxieties in a child” (p. 83). Research shows that both horizontally and vertically infected adolescents find HIV physically and emotionally painful, but it is only one of a multitude of perceived problems in their lives (Li *et al*, 2010). Other challenges include poverty, and the related malnutrition and inability to pay for travel to clinics; crime; violence; and drugs (Ferrand *et al*, 2010; Li *et al*, 2010). This is concerning given that “poverty, malnutrition and illness probably inhibit the maturation of children’s central nervous systems” and therefore negatively impact on their ability to cope (Ebersöhn & Eloff, 2002, p.82). The vast majority of adolescents in Li *et al*’s (2010) study had positive views of, and goals for, the future, however they were generally anxious about how those goals would be achieved. Research has found though that HIV-positive adolescents have a desire to communicate and be listened to, to learn more about HIV, be treated with respect, have more material support, and to be taught about life in broader terms (Li *et al*, 2010).

Ferrand *et al* (2010) found that for HIV-positive adolescents, irrespective of whether they were horizontally or vertically-infected, “the most common issues were psychosocial problems (56%), including lack of resources to seek help for these issues; erratic drug taking (36%), and lack of disclosure of HIV status (21%)” (p. 430). The main psychosocial stressors were having to look after sick family members, “stigma, difficulty in identifying with HIV-negative peers, anxiety about sexual relationships and future planning, and low self-esteem and feelings of hopelessness” (Ferrand *et al*, 2010, p. 430). Erratic drug taking was related to “delayed disclosure of HIV status, a desire to conform” and an inability of caregivers to supervise adherence (Ferrand *et al*, 2010, p. 430).

The desire to conform cannot be underestimated with this age group, as peer relations are so important at this time. Given their task of developing an identity (see 2.3.1), society's perceptions of what it means to be HIV-positive are likely to be especially important for HIV-positive adolescents. Kelly *et al* (2008) states the following when speaking about adults who become HIV positive and have to adjust to the diagnosis:

The fact that others... have preconceptions about the meaning of being HIV positive, often leads the HIV positive person to project such preconceptions onto his/her identity – at least at the level of how they see themselves in the context of relationships with others. (p. 231)

This idea is supported by Rohleder and Gibson (2006) in their understanding of how HIV-positive people acquire a “spoiled identity” (p. 40; see 2.2.2). Therefore, one must assume that, given the developmental task of developing an identity during adolescence, the above process of establishing a sense of self in relation to HIV would be that much more powerful in horizontally and vertically-infected HIV-positive adolescents.

Ferrand *et al*'s (2010) finding that disclosure is problematic for HIV-positive adolescents is supported by Rotheram-Borus and Miller (1998, in Fernet *et al*, 2007) who argue that “disclosure is a central factor in the lives of the youth living with HIV [because] the decision of when, how, with whom, and what to disclose – and for what goals – is difficult” (p. 109). Disclosure is so difficult because of the stigma surrounding HIV (see 2.2.2) and so disclosure necessarily opens adolescents up to the risk of being rejected and actively discriminated against.

Thus, while research is limited, both horizontally and vertically-infected adolescents experience significant challenges. This is in line with the context of HIV that was previously discussed (see 2.2). HIV-infection impacts on HIV-positive adolescents' biological development; their negotiation of intimacy, both in connection with peer relations and sexual relationships; their identity formation; and their psychosocial well-being. In addition HIV-related stigma is a significant concern in terms of their sense of self and disclosure to others, and therefore their ability to form intimate relationships.

#### 2.4.2 Vertically-infected adolescents and the challenges that are faced

As seen in the previous section (see 2.4.1) vertically and horizontally-infected adolescents experience a number of similar challenges during adolescence. However, it seems that vertically-infected adolescents should experience these same challenges differently to horizontally-infected adolescents in light of the fact that they have been positive their whole lives.

HIV can affect vertically-infected adolescents by delaying puberty; causing neurocognitive delays; and is often associated with behavioural problems, mental illness, decreased autonomy, and difficult peer relations due to stigma (Li, *et al*, 2010). This delay in development could serve to further stigmatise and increase “psychological distress” (Wiener & Lyon, 2006, in Fernet *et al*, 2007, p. 102). Kang *et al* (2008) state that “descriptive studies on the mental health needs of children living with perinatal HIV-infection suggest significant emotional and behavioural challenges” (p. 228). This could be worsened by the possible neurocognitive delays in this demographic (Li, *et al*, 2010).

Lesch *et al* (2007) state that “HIV-infected children usually have little control over when and how they are informed of their status, as their caregivers control the flow of information about their HIV-status to them and others” (p. 811). However, irrespective of when vertically-infected children or adolescents are told about their HIV-positive status, they would have grown up with a self-concept of themselves as sick. This would have been because either they were sick as children or it would have been implied by the fact that they have had to take medication their whole lives. Research shows though that delayed disclosure can have a negative impact both on drug adherence and on safe sex practices (Ferrand *et al*, 2010).

Kang *et al* (2008) use a developmental perspective to understand how HIV complicates “autonomy, peer [and romantic] relationships, and self-definition” (p. 228) for vertically-infected African-American adolescents. Developmental factors may influence vertically infected adolescents in three ways: firstly, moving from dependence to independence may be complicated by the need for caregivers to ensure that drug adherence occurs; secondly, the complications associated with disclosing one’s status may negatively impact on the development and maintenance of peer and romantic relationships; and thirdly, HIV-related

stigma may result in the formation of a negative sense of self (Kang *et al*, 2008). In addition, the “realisation of living with a stigmatised illness as an emerging young adult could influence what adolescents believe... due to contrasting societal perceptions of perinatal HIV infection and adult HIV infection – the former perceived as blameless victims and the later as belonging to marginalised groups” who acquired HIV through risky behaviour (Kang *et al*, 2008, p. 232). From this developmental perspective Kang *et al* (2008) therefore argue that changes in environmental, familial, health, and societal concepts of HIV will impact on an HIV-positive adolescent’s development.

In terms of the developmental task of identity, intimacy and sexuality Striepe and Tolman (2003) state that adolescents are negatively affected when they have to “interpret and cope with their sense of differentness when they do not conform to prescribed heterosexual gender ideologies and sexual scripts” (p. 529). It stands to reason that vertically-infected HIV-positive adolescents are therefore also negatively affected by their ‘differentness’ when it comes to their identity and more specifically their sexual identity.

Fernet *et al* (2007) conducted research in Canada with vertically-infected adolescents. They identified a number of themes related to the prevention of transmitting HIV: “HIV, a virus that is usually sexually transmitted; the condom, a means of effective protection; using condoms despite the fear of being rejected; asserting contraceptive arguments; integrating condoms into erotic scenarios; sharing their reality with their partner; [and] abstaining from certain sexual practices or temporarily from sexual activities” (Fernet *et al*, 2007, p. 105-107). Thus participants relied on three basic methods to prevent transmission: using condoms, disclosing their status, and abstaining (Fernet *et al*, 2007). However, it is important to note that for the participants the negotiation of condoms was dangerous because “condom use was closely linked in the minds of some youth with the risk of exposing their HIV status to their partner” and therefore their rejection by their partner and the subsequent ending of the relationship (Fernet *et al*, 2007, p. 108).

Fernet *et al* (2007) thus found that “it is the emotional and affective dimension of dealing with sexuality, and particularly so in the context of being HIV-positive, that appeared to pose the greatest challenge” (p. 109) for their vertically-infected participants. This was such that their “worries and anxieties went beyond those experienced by others their age and raise[d]

concerns about depression and self-esteem” (Fielden *et al*, 2006, in Fernet *et al*, 2007, p. 103), even meeting DSM diagnostic criteria (Kang *et al*, 2008).

And yet, “there have been few studies on sexuality, relationships, and HIV prevention issues among HIV-positive adolescents and fewer still that have dealt with youth living with HIV/AIDS since birth” (Fernet *et al*, 2007, p.101). Additionally, it is exactly the emotional aspect of sex, which adolescents are so concerned about, that is not addressed in support and educational services (Fernet *et al*, 2007). In other words, adolescents are not provided with a space in which to process “the emotional issues surrounding experimentation in romantic and sexual relationships” (Fernet *et al*, 2007, p. 109). Therefore Fernet *et al*. (2007) particularly suggest that “interventions that allow clarification of values in the context of different romantic and sexual relationships could help HIV-positive youth to evaluate their options and decisions in relation to their current and desired self-image” (p. 109) and enable safer sex practices.

The lack of research and supportive services for vertically-infected children and adolescents is surprising given that simply thinking theoretically it is easy to come to the conclusion that adolescence must be extremely challenging for the demographic. As stated above (see 2.3), adolescence is primarily concerned with the developmental tasks of identity and intimacy, necessarily implicating the development of a sexual identity (Epstein, 1991; Erikson, 1950). As vertically-infected youth live longer they negotiate increasingly more developmental milestones, which until recently they were not expected to meet (Kang *et al*, 2008).

Vertically-infected HIV-positive adolescents thus have to negotiate the normal developmental challenges associated with adolescence, but from a body that they have only ever known to be sick, even if the name of the sickness was not known. In addition, HIV is a disease that has direct links to sex and necessarily means potentially endangering any sexual partners that adolescents may have. HIV thus necessarily complicates the negotiation of intimacy, self and sexuality for vertically-infected HIV-positive adolescents.

Therefore, not only are vertically-infected HIV-positive adolescents negotiating the physical and emotional realities of living with HIV, as well as attempting to negotiate the developmental period of adolescence, but they are doing so from a body which they have only ever experienced as sick. Thus, it is argued that it is extremely challenging to be a vertically-infected HIV-positive adolescent. However, the lack of in-depth, psychological

knowledge concerning the demographic is detrimental in respect of providing adequate care, and guidance, for these adolescents.

## 2.5 Conclusion

Important to understanding vertically-infected HIV-positive adolescents is the context of HIV because this context necessarily impacts on the lived experience of being HIV-positive. Thus, the roll-out of ARVs and PMTCT medication, and therefore the reason for the vast numbers of vertically-infected adolescents in South Africa, was outlined. In addition, HIV was contextualised in terms of its politicisation, stigma, and its link to sex, sexuality, and constructs of gender.

This literature review also discussed the developmental stage of adolescence and its link to intimacy, sex and sexuality. It argued that HIV necessarily complicates intimacy and sexuality for vertically-infected HIV-positive adolescents. However, there is extremely limited research into vertically-infected HIV-positive adolescents (Fernet *et al.*, 2007; Ferrand *et al.*, 2010; Li *et al.*, 2010), and so this research hopes to start the process of bridging this gap.

## 2.6 Research aim and question

Thus, extending out of this literature and context, this project hopes to provide the beginnings of the most basic and fundamental exploratory knowledge towards understanding these adolescents in-depth. The aim of this research is therefore to explore the subjective experiences of vertically-infected HIV-positive adolescents, namely: how do vertically-infected HIV-positive adolescents experience intimacy, sex and sexuality in relation to their HIV status?

## **CHAPTER 3: Theoretical Underpinning**

### **3.1 Introduction**

This chapter will discuss HIV, adolescence and vertically-infected HIV-positive adolescents in relation to the psychodynamic, Kleinian object relations theory underpinning this research. It begins by discussing the theory broadly and then moves into a discussion of the self in terms of external reality, internal reality, transitional space, the unconscious mind and defences. Following this, Klein's development of the self from the paranoid-schizoid position to the depressive position is discussed. Lastly, sex, sexuality and vertically-infected HIV-positive adolescents are discussed from a psychodynamic, object relations perspective.

Lemma (2003) states that “psychoanalysis is an umbrella term covering a number of theoretical schools which, whilst all originating from and honouring some of Freud's ideas, have since evolved very different theories” (p. 17). Psychoanalysis is thus complex and multifaceted. However, it “has to do with the unconscious, with repression (and hence conflict), with sexuality and with death (non-being)” (Hayes, 2012, p. 146), and thus fits well with the themes of HIV.

A school of thought that developed out of early psychoanalysis is object relations theory. The central concept of object relations theory is that when human beings are born their most fundamental need is for a connection and relatedness with others (Epstein, 1991). It holds that “we are driven primarily by our attachment needs, that is, we are driven to form relationships with other people” (Lemma, 2003, p. 40). Thus, human beings develop in interaction with others (Lemma, 2003). Object relations theory has been used for this research because:

It can seek to understand how people actively integrate feelings and experiences into more or less coherent wholes [i.e. identities]; how they relate self-perceptions and perceptions of others to the available cultural meanings attached to sexual terms; and finally, how in the dialectics between individual action and social categorisation, the categories themselves can be challenged and transformed. (Epstein, 1991, p. 862)

This research is located specifically in Klein's object relations theory, though, because of her understanding of phantasies, the complexities of relationships, and the paranoid-schizoid and

depressive position. This is because Klein's theory is unique in its ability to provide a framework for understanding how external realities and social constructions, particularly those related to HIV, sex and intimacy, come together within vertically-infected, HIV-positive adolescents' bodies, and how the adolescents intrapsychically and subjectively process them within the context of their internal representations and adolescent developmental challenges. Klein can thus be used to understand how vertically-infected HIV-positive adolescents' sense of intimacy, sex and sexuality has been impacted on by both their internal and external reality and object relations.

### 3.2 Object relations theory

Ivey (1990) defines object relations theory as:

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

Thus, one of the major contributions of object relations theory is that it brought about a focus on how children develop and an acknowledgement of the importance of the relationship between the child and their primary caregiver (Lemma, 2003). Long (2009) states that "HIV-positive mothers enter into contradictory identities simultaneously: the denigrated, abject and feared identity of being HIV-positive and the idealised identity of motherhood, with all its associations of purity and goodness" (p. 2). HIV-positive motherhood thus involves a complex coming together of "loss and gain, creativity and destructiveness" (Long, 2009, p. 2). It is likely that participants' mothers would have been concerned about infecting their children, if only in fantasy (Long, 2009). Long (2009) states that academia assumes HIV-positive mothers to be "*bad* mothers", however research shows that an HIV-positive diagnoses in itself does not result in decreased care and bonding, but rather the progression of disease to AIDS (Long, 2009, p. 3).

Ultimately Long (2009) states that for HIV-positive mothers "making sense of oneself as a mother – for one's baby, but also for oneself – means negotiating the strong emotional resonances of HIV-positive motherhood through very powerfully and socially sanctioned

discourses of both motherhood and HIV” (p. 3). Object relations theory holds that this process would have necessarily impacted on this research’s participants’ sense of self, other and the world.

### 3.2.1 The self: External reality, internal reality, and transitional space

According to the object relations framework “psychological life begins with [the] distinction between internal and external and the associated somatic fantasies of internalisation and externalisation” (Ivey, 1990, p. 7-8). This is because when a baby is born one of the first things it learns is to distinguish between what is inside and outside of itself (Winnicott, 1971). Winnicott (1971) states that

Of every individual who has reached to the stage of being a unit with a limiting membrane and an outside and an inside, it can be said that there is an inner [and outer] reality to that individual... [and] the third part of the life of a human being, a part that we cannot ignore, is an intermediate area of experiencing, to which inner reality and external life both contribute. (p. 2)

There are thus three kinds of reality in object relations theory: external reality, internal reality, and transitional space (Aitken, 2001). External reality refers to the ‘objective facts’ that exist in the world (St. Clair, 2000). These are “observable objects” which could be documented by an outside observer (St. Clair, 2000, p. 6).

For example, a key problem identified in the literature review (see 2.4), and an important external reality for this research’s participants, is poverty. Smiley (2004), in her psychodynamic work with homeless, HIV-positive men states that from the beginning poverty “shapes their world, tragically limiting their access to social and emotional privileges that would otherwise have more happily influenced their lives” (p. 254-255). Thus, poverty would have been a harsh reality in terms of the level of physical care participants were able to receive and how in tune their mothers were able to be with them. A mother who has not eaten all day will not be able to be as in touch with her child as a mother who has eaten. In a similar way, if a mother is physically sick this will be an external reality that will have direct implications for her ability to care and her relationship with her child (Long, 2009).

On the other hand, internal reality is how someone represents and experiences the external, 'observed' world in their psyche (St. Clair, 2000) such that it "come[s] to reside inside our skin boundary" (Ivey, 1990, p. 8). Ivey (1990) states that it thus "describes the phenomenological experience of simultaneously dwelling in both a public and a private world" (p. 6). Internal reality is important for HIV because it means that people who are HIV-positive will bring society's concept of HIV into themselves. For example, Long (2009) states that "in the inner world where fear is as important as reality, the existence of the virus inside one's body encourages one to contemplate death" (p. 2-3).

Internal representations or object structures are "relatively stable, enduring and semi-autonomous psychic configurations comprising self-representations and object-representations linked by an emotional charge" (Ivey, 1990, p. 10). Importantly, "all internal objects have a self-component as well as an object-component... every reference to an internal object thus necessarily implies an object relation" (Ivey, 1990, p. 10). Thus, the "self and other are inextricably linked" (Ivey, 1990, p. 11) such that "internal object and internal object relations provide not only templates for ways of relating but also the raw material for selfhood" (Thomas, 1996, p. 291). This can be seen in Rohleder and Gibson's (2006) concept of HIV-positive people acquiring a spoiled identity where others' concepts of HIV have been taken into the self and become a part of the stable internal psychic structure.

This internal reality is so dominant that "our primary mode of comprehending the world is... not rational appraisal but unconscious fantasy" such that an individual's "fantasies about people do not correspond to in a one-to-one fashion with the "real" people in the external world" (Ivey, 1990, p. 4 & 5). In other words, an individual's internal objects or unconscious fantasies of the external world and themselves regulate and mediate all their negotiations with the external world (Ivey, 1990). Object relations thus focuses on the psychodynamic, subjective experience of how "people react to and interact with not only an actual other but also an internal other, a psychic representation of a person which in itself has the power to influence both the individual's affective states and his overt behavioural reactions" (Greenberg & Mitchell, 1983, p. 10). The primacy of internal representations in influencing how individuals interact with the external world means that this research "is not concerned with literal facts but rather literary facts" because psychological truth lies in how an individual perceives things rather than how they really are (Ivey, 1990, p. 5). The "process by which external (interpersonal) relations are transformed into intrapersonal (intrapsychic)

ones, thereby becoming an integral part of the developing self” is called internalisation (Ivey, 1990, p. 20). This is done through introjection, which produces an introject or internal object.

HIV-related stigma is a prime example of how external reality is internalised into an introject such that the introject dominates an individual’s interaction with the world. Rohleder and Gibson’s (2006) concept of a spoiled identity occurs because individuals internalise HIV-related stigma and thus create an introject of the self as bad. This introject then becomes a stable part of an individual’s self-concept to the extent that active discrimination is not required for a person to experience HIV-related stigma because the individual has already internalised it (Deacon *et al*, 2009).

The third area of importance is transitional space. Transitional space is where internal and external reality come together into something that is not quite either internal or external reality but a negotiation of the two (Aitken, 2001). Ivey (1990) describes it as a “shared reality” (p. 17). Winnicott refers to it as “potential space” (Ivey, 1990, p. 17-18) and a “resting-place” (Winnicott, 1971, p. 2). This is the space where people meet, for example an HIV-positive mother and her child. It is therefore the space where “introjections of other people can be identified and made part of one’s self” (Thomas, 1996, p. 291) and as such is the important area in which people ‘become’ (Ivey, 1990; Thomas, 1996). Andersen and Przybylinski (2012) support this premise that the self is constructed in relationship with others. Importantly though, these others are not restricted to only being those present in early childhood, but rather to anyone throughout a person’s lifespan that becomes significant (Andersen & Przybylinski, 2012).

From an object relations perspective “the self starts off as a potential in the new-born infant” and given the right environment “develops into a whole self – that is, a person who is able to distinguish between Me and Not-me” (Abraham, 2007, p. 295), internal and external reality. For Winnicott the self aims for the phenomenological experience of “feeling real” (Abraham, 2005, p. 295). However, “the issue of mother-infant attachment in the context of HIV is particularly loaded” (Long, 2009, p. 93). This is partly because the “mother-infant relationship is always under threat and HIV silently exists in between the (not) nursing mother and her baby” (Long, 2009, p. 142). It is as if HIV becomes a third person in the relationship between the HIV-positive mother and her possibly HIV-positive child.

Traditionally, transitional space is created first through the use of a transitional object. This is where an object, like a blanket or teddy bear, comes to represent the dominant attachment figure for the child in order to ease the pain of separation. However, this is only possible if the child experiences his or her attachment figure as good and loving. Ivey (1990) argues that the use of a transitional object allows for symbol formation, which in turn develops into creative symbolism. Without these “language, culture, art, play, religion and creativity” would not be possible (Ivey, 1990, p. 19). This means that “the collapse or rupture of transitional space through deficient mothering results in the inability to live symbolically” (Ivey, 1990, p. 19) and negatively impacts on the experience of intimacy.

Object relations theory’s concept of external reality, internal reality, and transitional space means that the theory holds that there is a constant negotiation and interplay of borders between representations of internal realities of the self, and representations of external realities of the social and cultural world and thus “multiple and divergent meanings and therefore subjectives” (Aitken, 2001, p. 112). Long (2009) states that psychoanalysis is useful when thinking about the experience of being HIV-positive because of its ability to “acknowledge that this kind of experience is one of both internal struggle and struggle against broader social discourses” (p. 97). Object relations theory thus allows people to “become” as a result of the interplay between culture, society, politics, and something from within (Winnicott, 1971, in Aitken, 2001, p. 113). People bring something of themselves to their culture and external world, and renegotiate it, and in this way shape the way that they interact with that culture and external world (Aitken, 2001). Therefore, human nature is fluid and flexible in response to changing social and cultural realities (Epstein, 1991). For HIV-positive adolescents this means that there is a constant negotiation between their internal and external realities such that nothing is fixed and everything is negotiable. Therefore, an internalised spoiled identity, for example, can be changed such that the experience of the self, others and the world are also changed.

### 3.3 Internal reality: The unconscious mind and defences

#### 3.3.1 The unconscious

Freud found through the analysis of his own dreams that “ordinary daily disappointments had accrued a traumatic-like force because they were underpinned by hurts that had accumulated

over an extended period, dating all the way back to childhood” (Likierman & Urban, 1999, p. 21). This is because negative experiences from the past remain in the unconscious (Likierman & Urban, 1999) and have “a determining effect upon the whole of our later development” (Freud, 1905, p. 175). The concept of the unconscious means that there is always far more going on for human beings than they are ever consciously aware of, such that “much of the self is hidden and our subjective experience of selfhood is partial” (Thomas, 1996, p. 312). Therefore, in line with object relations theory, “the closest we can get to an overall picture of ourselves is through the eyes and ears of another person” (Thomas, 1996, p. 312).

Brinich and Shelley (2002) state that like Freud “Klein was more concerned with dissecting the self, understanding what went on beneath the surface, than understanding the self per se” (p. 28). Therefore, both Klein and Freud assumed the existence of the self and rather focused on understanding the, often unconscious, parts of the self (Brinich & Shelley, 2002). The concept of parts of the self is consistent with psychodynamic understandings of the self (Thomas, 1996). Thomas (1996) states:

Subjective experiences of selfhood, the observations of writers, and psychodynamic theories based on clinical observations, all suggest that selfhood may be a matter of constructing a single reality by which to live, but that we do this despite our experience of several or many realities – several selves. (p. 315)

This fits with object relations’ understandings of how the self is constructed by introjecting multiple significant others and relationships (Thomas, 1996). However, this “exists in tension with the need to preserve a familiar, safe and unitary sense of self” (Thomas, 1996, p. 319).

Thus, the unconscious, internal reality is central to understanding Klein. For Klein, “nothing is seen simply as it is: some kind of unconscious fantasy is attached to every perception: structuring, colouring and adding significance to it” (Segal, 1992, p. 29). These unconscious fantasies she termed “phantasies, to distinguish them from conscious fantasies” (Segal, 1992, p. 29). Thus, this research’s participants’ phantasies serve to shape and colour all of their experiences of themselves, others and the world.

Fundamental to understanding the unconscious is that it cannot help but express itself even though, in virtue of it being part of the unconscious, people are rarely consciously aware of it.

Hinshelwood (1994) states that the unconscious is “active in influencing thoughts, feeling, relationships, attitudes and behaviour in a way which is completely unknown to the person” (p. 10). For example, the irrationality around not conforming to safe sex practices (Hayes, 2012) can be explained by the unconscious. This means that people may intentionally, although unconsciously, behave in ways that are not in their best interest (Lemma, 2003). However, it is important to remember that unconscious phantasy does not correlate in an identical fashion to outward behaviour (Long, 2009). For example, HIV-positive mothers’ fears of infecting their children do not necessarily impact negatively on the bond between mother and child (Long, 2009). The unconscious also means that people can mislead themselves and others (Lemma, 2003).

For Klein, fundamental for any individual is the meaning that they attach to things based on their own phantasies (Segal, 1992). This meaning arises “out of the interaction between their emotions and their perception of the world around them and inside them they create phantasies which they use to understand the world” (Segal, 1992, p. 31). For example, stigma is not simply absorbed into a person’s sense of self but is rather digested and interpreted within the context of a person’s beliefs about themselves, HIV and the world. For Klein (1952), “altogether, in the young infant’s mind every external experience is interwoven with his [sic] phantasies and on the other hand every phantasy contains elements of actual experience” (p. 158). Thus this research’s participants would have necessarily been influenced by their phantasies within the interview context, in addition to the actual interview.

Just as internal reality is more powerful than external reality, phantasies are more important for Klein in determining an individual’s emotional state than the real people around them (Segal, 1992). For example, Long (2009) states that “questions of what one is to accomplish in one’s life, as well as how one is going to die – universal questions that most of us spend a fair amount of time avoiding – become more urgent with an HIV-positive diagnosis” (p. 2). Thus, “phantasies strongly influence expectations and interpretations of real events in the world” (Segal, 1992, p. 31). However, parents’ behaviour is important in either confirming or disproving a child’s phantasies (Segal, 1992), as is anyone else with whom an individual comes into contact.

Klein saw an infant's phantasies as being completely, utterly, and overwhelmingly terrifying, sadistic, violent, and aggressive. This is so much so that "however well or badly parents behaved reality was less monstrous than the child's phantasies" (Segal, 1992, p. 29). Klein thought that many phantasies involve "attacks on the mother or parts of her body" (Segal, 1992, p. 31). This is because the baby's relationship with the mother begins with breastfeeding, which involves biting, sucking, and literally trying to ingest and eat the mother (Segal, 1992).

However, the infant is also born needing a relationship with the mother and loving her. Thus, "much of Klein's work examines the relationship between aggressive and loving impulses and phantasies" (Segal, 1992, p. 32). This is particularly useful for this research given how life and death is such an important theme related to HIV. For example, Long (2009) states that HIV-positive mothers represent "the coexistence of birth, death and sexuality in the feminine and maternal body responsible for family and children" (p. 96). This, together with what the HIV-positive child represents, means that the relationship between HIV-positive mother and child is extremely complex (Long, 2009). As such, capturing the lived experience of being HIV-positive means "finding a multitude of positions, identities, meanings and emotions rather than finding a fixed and definable entity" (Long, 2009, p. 81).

For Klein, "phantasies give 'body' and expression to emotional states" (Segal, 1992, p. 30). In other words, people externalise their phantasies onto and into the outside world. Thus, Segal (1992) states that for Klein "phantasies are about doing something to someone, an object distinct from the self. This 'object' could be a part of the self separated off and objectified, that is, seen as 'not me'" (p. 31). This means that the participants for this research are not simply passive receivers of their lives. They project out into the world parts of themselves in order to find the best way of coping and negotiating their lives.

### 3.3.2 Defences

Object relations and psychodynamic theory holds that "development cannot occur without a measure of psychic pain or anxiety" (Lemma, 2003, p. 200). Malan (1979) argues that defences arise as a way of coping with anxiety, and that anxiety exists because there is a hidden feeling that the person cannot bear to know. Therefore, defences "exist to protect us from perceived danger and the ensuing psychic pain" (Lemma, 2003, p. 206). This means that

defences are “protective shields that represent attempts – however misguided or pathological – to manage intrapsychic and interpersonal conflicts” (Lemma, 2003, p. 203). Thus, psychoanalysis “allows [the] conflicts and irrationalities associated with an HIV-positive diagnosis to be examined not as failures, but as inevitable in the face of painful knowledge” (Long, 2009, p. 97). Implicit in this is the fact that psychoanalysis allows for the “recognition of the unspeakable and unbearable” themes related to being HIV-positive that people otherwise prefer to ignore (Long, 2009, p. 98).

Defences are so ingrained in an individual’s psychological makeup that psychoanalysis argues that the self itself is actually a “defensive structure which protects a sense of wholeness” (Thomas, 1996, p. 282). This is because the self arises out of the transitional space of “unreality and creative illusion” as a protective measure (Thomas, 1996, p. 307) against the pain of existence. Thus, fundamental to understanding defences is the fact that they are adaptive and a means of coping. Without defences people would become psychotic. That people make use of defences is unquestionable. Therefore, the question to be asked when considering defences is not whether there are defences, but rather how useful and flexible they are (Lemma, 2003). This is because defences that are used too rigidly or too much of the time become more unhelpful than helpful in that “they prevent us from becoming aware of what troubles us and so prevent us from developing a relationship with both our internal and external reality” (Lemma, 2003, p. 207). Lemma (2003) states that defences work, unconsciously usually, in the following manner:

Defences falsify, negate or distort reality in order to avoid situations experienced as dangerous. They act primarily to obliterate awareness to ensure that anxiety does not break through into consciousness... [Thus] defences can alter our perception of ourselves, of others, of ideas or feelings. (p. 206)

The problem with defences is that they can “distort or exclude information or affective experiences” (Lemma, 2003, p. 203). Therefore, when considering defences it is important to take into account both what the defence is trying to avoid and also what it allows for the person to cope with (Lemma, 2003). Holder-Perkins and Akman (2006) state that living with HIV is an “emotional rollercoaster” such that “emotional responses may elicit maladaptive defence mechanisms, such as denial, regression, or isolation of affect” (p. 72). However, these defences also allow the person to cope with being HIV-positive.

The concept of projection is important to understanding defences. This occurs when “what is inside is misunderstood as originating from outside of the self and is attributed to another person/source” (Lemma, 2003, p. 212). These can be feelings or parts of the self (Lemma, 2003). The phenomenon of stigma is a typical example of the defensive use of projection (Deacon *et al*, 2009; see 2.2.2).

The defences that participants in this research make use of will be indicative of their early and current experiences, and how they are unconsciously negotiating these experiences. Thus, the concept of defences is pivotal to understanding the participants in this research.

### 3.4 Klein’s development of the self

#### 3.4.1 The paranoid-schizoid position

Klein thought that anxiety is both present and unavoidable from birth (Lemma, 2003). This is due to the fact that every experience, including any kind of emotional state, that the infant experiences is so new and unfamiliar that it is terrifying for the infant. In addition, as discussed previously, when the baby is born its first task is to learn to differentiate between what exists inside of it and what exists outside of it; and so Klein argued that the baby is born with “a terror that the self will be overwhelmed or engulfed by another or cease to exist altogether” (Lemma, 2003, p. 202). In other words, the baby experiences an intense fear that something bad from the outside world is going to harm it. These fears of annihilation are referred to as “persecutory anxieties” and are extremely primitive (Lemma, 2003, p. 202).

In order to protect itself “the infant adopts phantasies of a defensive kind when it is overwhelmed” (Hinshelwood, 1991, p. 180). Bateman and Holmes (1995) argue that for Klein:

The infant encounters and introjects two sets of contradictory experiences: ‘good’, satiating, nurturing feelings associated with successful feeding, warmth and tactile contact with the mother; and ‘bad’, associated with separation, abandonment, hunger, wetness and cold. These form the nucleus of feelings of love and hate. (p. 56-57)

Importantly though, the infant “can only maintain psychic equilibrium by keeping good and bad apart” (Bateman & Holmes, 1995, p. 57). In other words, the infant cannot tolerate holding good and bad together. Therefore, to defend against these contradictory experiences and the baby’s anxieties previously described, the baby makes use of primitive, paranoid defences and splitting.

Splitting refers to the baby identifying things as either completely ‘good’ or completely ‘bad’, and “introject[ing] and indentify[ing] with the good ‘me’ experiences, while splitting off the bad ‘not me’ feelings and projecting them outwards” (Bateman & Holmes, 1995, p. 57). In this way the infant does not realise that the loving mother who feeds it is the same mother who sometimes does not immediately attend to its needs.

Klein argues that “projective mechanisms allow us to forcefully allocate, in phantasy, aspects of the self to the [external] object” (Lemma, 2003, p. 212). There are two levels of projection: projection and projective identification. Segal (1992) states the following:

Projection can be thought of as *perceiving* someone else as having one’s own characteristics; projective identification involves a more active *getting rid of* something belonging to the self into someone else. Projective identification involves evoking in someone else aspects of the self which one cannot bear. (p. 36)

However, “the process of sorting out good and bad objects involves projection of parts of the self” (Segal, 1992, p. 34) and so necessarily requires, in addition to splitting the external object, a splitting of the self. Projective identification involves a much deeper split of the self than projection (Segal, 1992).

The use of splitting is initially adaptive because it allows the baby to “distinguish fully between love and cruelty and to feed trustingly” (Segal, 1992, p. 33). In addition, it “enables a core sense of self-worth and goodness to hatch, uncontaminated by bad feelings of rage and disappointment” (Bateman & Holmes, 1995, p. 57). This is because “the boundary between self and other is in some ways denied” and so the infant views itself as being identical to the idealised ‘good’ (Segal, 1992, p. 35).

For this reason people revert to the paranoid-schizoid position in times of stress as a way of coping (Segal, 1992; Smiley, 2004). HIV is one of those times of stress. This is because being HIV-positive involves “having to face prejudice, treatment decisions, illness and death” (Nuttall, 1998, p. 45) due to its potential to be terminal, which is worsened by the stigma attached to it (Smiley, 2004). Thus, Nuttall (1998) states that HIV, with its connection to “sexuality and the rejection of life, brings about a traumatic clash of the phantasy of defence with the reality of illness and death” (p. 458). This conception of HIV fits perfectly with Klein’s understanding of phantasy and the paranoid-schizoid position. Klein’s understanding of the terror of phantasies, being engulfed, annihilation and ceasing to exist align with the “real-world rejection and disconnection” associated with HIV (Smiley, 2004, p. 254). In other words, HIV serves to confirm the terror of an individual’s phantasies.

A similar splitting can be seen in society as a whole as a way of coping with the terror of HIV. Society has split HIV off as a bad, hated object as a way of distancing themselves from HIV (Deacon *et al*, 2009). This even extends to the academic work on HIV. For example, Long (2009) states that literature tends to split HIV-positive mothers as either good or bad, not acknowledging “a more realistic position that they may be neither and both” (p. 82).

Splitting, however, is not adaptive in the long term. This is because splitting is “a distortion of reality” (Segal, 1992, p. 33). Segal (1992) states that splitting “creates larger-than-life people and larger-than-life emotions, unmodified by their opposites... so that, for example, if someone or something is defined as bad, any goodness in them is simply not seen” (p. 34). In reality no one is inherently ‘good’ or ‘bad’ and so the idealised, loving mother, for example, will never be able to maintain her idealised status. This, in addition to the paranoid-schizoid’s persecutory anxieties, makes the world significantly anxiety provoking because nothing remains as it was originally perceived i.e. completely good or bad. Therefore, adults operating from this position are distrustful and suspicious and tend to “feel that they have to care for themselves since there is nobody else [they trust] to care for them” (Segal, 1992, p. 35).

In addition, and possibly more importantly, splitting involves not only the splitting of the external object but also a splitting of the self (Segal, 1992). Thus, part-objects are created of the self and the world (Ivey, 1990). Holder-Perkins and Akman (2006) state “the psychological distress linked with the social and physical pressures of HIV infection manifest

in the form of depressive symptomatology, including heightened anxiety, worries, tensions, perceived stress, and avoidant, intrusive, and overwhelming thoughts” (p. 72). Therefore, people who are HIV-positive need to defend against these feelings. This is often done through splitting such that the self and HIV are thought of as “part objects defined by reproductive organs, damage and infectiousness” (Long, 2009, p. 82). This means however that someone operating from the paranoid-schizoid position will struggle to establish a coherent, secure sense of self.

### 3.4.2 The depressive position

Contrary to the paranoid-schizoid position, the depressive position is the ability to withstand the pain of observing a relationship to which one is not a part; and to relate to whole objects, that is to hold that an object is both loved and hated and separate from the self (Hinshelwood, 1991). The depressive position comes about as a result of the successful resolution of the oedipal complex (Hinshelwood, 1991).

Freud argued that people are sexual from birth and pass through a number of psychosexual stages (Lemma, 2003, p. 23). These include the oral (0-1 years), anal (1-3 years), and phallic (3-5 years) stages (Lemma, 2003, p. 23). The phallic stage, where children become aware of genitals and sex, is the stage where Freud thought that the oedipal complex occurred (Lemma, 2003).

Freud (1905) argued that “it is self-evident to a male child that a genital like his own is to be attributed to everyone he knows” (p. 195). This idea resulted in Freud’s early work on the oedipal complex which argued that little boys suffer from a fear of being castrated and little girls experience penis envy (Freud, 1905). This later developed into the well-known idea that little girls experience rivalry with their mothers because their sexual energy is directed towards their fathers; and little boys experience rivalry with their fathers because their sexual energy is directed towards their mothers.

The resolution of Freud’s oedipal complex was that the little boy would repress his sexual feelings towards his mother and identify with his father; and the little girl would repress her feelings towards her father and identify with her mother (Lemma, 2003). This identification,

Freud thought, involved the child relating to the same-sex parent by “incorporating their values, standards and sexual orientation” (Lemma, 2003, p. 24).

Similar to Freud, in Klein’s (1932) “experience it is the regular thing for quite young children to enter into sexual relations with one another” (p. 166). Therefore, she thinks that “children possess a sexual life which finds utterance both in direct sexual activities and in sexual phantasies” (Klein, 1932, p. 164). She states though that the development of sexuality is complicated and impacted on by a multitude of factors (Klein, 1932). This is in line with Worthington *et al*’s (2002) biopsychosocial factors impacting on sexual development. This means that in the case of vertically-infected HIV-positive adolescents the presence of HIV in the adolescents’ bodies will impact on the adolescents’ sexual development.

Klein agreed with Freud that a baby’s focus moves from the oral, to the anal, and then to the genital areas, but unlike Freud she thought that there was “constant movement from one to the other and back again” (Segal, 1992, p. 33). Ultimately, Klein’s understanding of the importance of phantasy led her to a very different understanding of the oedipal complex to Freud. Firstly, it led her to show the “pregenital components (oral and anal) of oedipal phantasies”, and so establish that the oedipal complex begins pregenitally or very early on in life (Hinshelwood, 1991, p. 57). Secondly, Klein argued that internal parent phantasies or objects derived from the oedipal complex are more important than the actual, real world parent figures (Hinshelwood, 1991). This is such that:

Rather than the parents creating guilt about sexual thoughts in children who otherwise would not fear them, Klein thought this guilt could arise from the child’s own phantasies, in which the child attributed to parents thought which did not necessarily belong to them at all. (Segal, 1992, p. 29)

For example, Segal (1992) states that:

It was the boy’s unconscious jealous, angry or envious impulses to cut off his father’s ‘willy’, for example, which were most important in determining his fears of being castrated himself [not any threats made by his father]. It was the girls’ angry, jealous or envious desires to take over, spoil and destroy the contents of her mother’s breast

and body which led her fear of her mother doing the same to her [not anything that her mother had done]. (p. 29)

Thirdly, and possibly the biggest implication of Klein's work on phantasies, was the discovery that:

The oedipal complex is not simply a love for the parent of the opposite sex and a hatred for the rival parent of the same sex. In fact she found very mixed feelings, and therefore came to emphasise the inverted Oedipus complex in which little girls [also] both love and identify with mother, and boys both love and identify with father. (Hinshelwood, 1991, p. 61)

This means that in addition to Freud's positive oedipal complex, infants simultaneously also experience the inverted oedipal complex. The latter is when the infant identifies with and loves the parent of the same sex and hates the parent of the opposite sex; and the former is when the infant hates the parent of the same sex and loves the parent of the opposite sex (Hinshelwood, 1991). Klein thought that "the oscillations between the positive and negative oedipus complexes in the course of the infant development resulted in both loved internal objects and hated ones" (Hinshelwood, 1991, p. 63). Eventually, with the necessary environmental context, the loved and hated objects will join to become one internalised object that is both loved and hated (Hinshelwood, 1991).

Thus, modern understandings, and this research's understanding, of the oedipal complex focuses less on sexuality and more on the relationship dynamics. Hinshelwood (1994) states that the oedipal complex essentially "refers to links of loving and being loved – hating and being hated – in the triangular situation... [for example,] loving one parent and hating the other" (p. 179). Therefore, the oedipal complex does not require a father necessarily but rather a dominant attachment figure and an other. From this perspective the oedipal complex occurs because the infant assumes that "since his [sic] mother has always looked after all his [sic] bodily and emotional needs, and apparently regards herself as responsible for satisfying these, he [sic] assumes that she will similarly continue to be responsible for satisfying his [sic] genital desires" (Likierman & Urban, 1999, p. 23-24). When this does not happen the child starts to realise firstly, that their mother is separate from them and secondly, that their mother has a relationship with an other, usually their father, to which they are not a part

(Bateman & Holmes, 1995). In other words, the oedipal complex is significant because it causes the “shift from dyadic to triadic relationships” (Lemma, 2003, p. 41). Having done this Bateman and Holmes (1995) state that

the child ‘loses’ the mother, but gains the capacity to think – creative thought requires the bringing together of ideas in new combinations – and to lead his or her own life, having internalised the parent couple. He or she also ‘gains’ the father as a real object, and not just as an alternative mother. (p. 54)

This has a fundamental impact on the infant’s developing psyche because the child begins to learn that there is a boundary between them and their mother and so that they are separate human beings. In addition, the ability to be an observer who is not a part of a relationship is “fundamental to our capacity to communicate with others based on an understanding that they may have different intentions, feelings or desires to our own” (Lemma, 2003, p. 39).

Thus, the oedipal complex is pivotal to a vertically-infected HIV-positive child’s development. In addition to impacting on the child’s sexual development, its resolution, or not, impacts on the child’s ability to see people and the world as both good and bad. If resolved successfully it allows for the child to be able to tolerate complexity, ambiguity and others as separate from the self. However, the realities of HIV, and the chances of having had significant attachment figures pass away, complicates the oedipal complex for these adolescents.

This means that the depressive position, or whole object relating, “is a developmental accomplishment rather than a biological given” (Ivey, 1990, p. 13). However, Segal (1992) argues that for Klein “there was a continuous tension between paranoid-schizoid mechanisms and depressive mechanisms” such that “people constantly move from one to the other and back again” depending on their stress levels (p. 33). For example, an HIV-positive diagnosis would at least initially move a person back to operating from the paranoid-schizoid position.

The depressive position involves the individual realising “that the very object which he hates and fears is also the one he loves and depends on” (Bateman & Holmes, 1995, p. 57). This brings together “good and bad, love and hate” (Bateman & Holmes, 1995, p. 57). This realisation is not an entirely pleasant process though, as it awakens in the baby a sense of

guilt as they fear that their hate may have done damage to the loved object (Lemma, 2003). This results in the baby attempting reparation with the now both loved and hated object (Lemma, 2003). In general the depressive position “brings with it the awareness of loss, grief, sadness and mourning” (Segal, 1992, p. 28). The individual also has a sense of themselves as being separate individuals, which is a painful realisation.

However, the pain is worth it as the depressive position results in an individual beginning to “integrate experience rather than... split[ting] it” (Segal, 1992, p. 38). The individual therefore, starts to experience and tolerate ambivalence (Lemma, 2003) and so starts to relate to objects or others as whole objects, as opposed to split, part objects, and so experience themselves as whole too (Segal, 1992).

For an individual operating from the depressive position the world is no longer experienced in such extremes as “a good experience does not mean heaven forever; its loss is not the end of the world” (Segal, 1992, p. 38) and so the world becomes a safer place. In addition, their ability to whole object relate is fundamental for healthy relationships in the future. This is because “in order to be able to care and share, others have to be seen as human beings with their own characteristics, rather than simply parts of the self” (Segal, 1992, p. 40).

Someone operating from the depressive position is far more resilient and has more internal ego strength than someone operating from the paranoid-schizoid position. This stronger ego strength then leads to the use of more mature defences. Thus, in terms of this research it would be beneficial for participants in the long-run if they were operating from a depressive position. However, given the presence of HIV in their lives, it seems unlikely that this will be the case.

### 3.5 Sex and sexuality from a psychodynamic and object relations perspective

According to Klein (1932) “the decline of the oedipus conflict normally ushers in a period in which the child’s sexual desires are diminished though by no means entirely lost” (p. 166). However, if a child has “an excessive sense of guilt” and anxiety then this decline in sexual desires tends not to happen, in fact the guilt and anxiety serve to reinforce sexual desire (Klein, 1932, p. 170). Therefore, while sex is a contested space for the participants in this research, this does not mean that that they will have no desire as the participants’ guilt and

anxiety surrounding sex might reinforce their sexuality. Under normal circumstances, during puberty adolescents' sexual desire will increase again but directed now towards peers rather than parent figures (Klein, 1932).

Hayes (2012) states that psychoanalysis is unique in its ability to think critically about sexuality. Therefore, it is in a unique position from which to consider HIV/AIDS. This is significant because "the fact of AIDS confronts us as a stark reality, *and* as unconscious projected fears and phantasies" (Hayes, 2012, p. 150).

However, the unconscious, "beyond language', 'beyond speech'" facets of sex make it extremely challenging to talk about sex and desire in its entirety (Hayes, 2012, p. 155). In addition, much of sexuality is repressed (Hayes, 2012). Repression is "unconsciously purposively forgetting" because one cannot bear to know (Lemma, 2003, p. 211). Berger (2005 in Hayes, 2012) states that "by definition, what is repressed is unconscious, and what is unconscious is not known by us" (p. 155). Therefore, desire and sexuality is impossible to talk about in a fully knowing way. Added to this the previously discussed (see 2.2.3) fact that "sex is not just one thing, nor does it have a stable meaning across culture and time, and hence signifying (sexual) desire envelopes language while sliding through it 'in disguise'" (Hayes, 2012, p. 155). Therefore, Hayes (2012) states:

'Sexual knowledge' is a bit of a misnomer... the 'truth' of sexuality is not waiting in the wings of empirical research or in lots of so-called 'straight talk' about sex, and... much to do with our sexual lives is both non-rational and irrational. (p. 57)

Thus, Hayes (2012) further states:

Knowledge about sexuality is not really what might be called positive knowledge, and in any case the positive knowledge is not what gives us such a tough time in making sense of sexuality and desire. Sexuality and desire do not seem to be primarily about knowledge at all, but seem to be more about lived experience, of how we try live amongst people in the midst of the dialectics of desire. (p. 161)

Part of what makes sex so unknowable is that from a psychodynamic perspective sex brings with it the chance of experiencing "'too much pleasure' and the unbearable slide into non-

being” (Hayes, 2012, p. 159). Therefore, sex is as connected with pleasure and enjoyment as it is to death (Hayes, 2012). This is in terms of the physical realities of sex’s connection to HIV/AIDS, but more so symbolically: “the ‘death’ of not being the object of someone’s desire, the ‘death’ of desiring what we lack, in short the absence of being able to be part of the signifying (and desiring) practices that constitute our identity” (Hayes, 2012, p. 159).

For this reason, Hayes (2012) states that “psychoanalytically speaking, within the discourses that circulate around HIV/AIDS there is no such thing as safe sex” (p. 157). Sex can be made physically safe; however because of its unavoidable links to the oedipal complex and the phantasies attached to it, especially in relation to HIV/AIDS, sex is always psychologically dangerous. Paradoxically though, this danger adds to sexual desire as “much of our (persistent) interest in sex has to do with its edgy excitement, vulnerability, risk, desire, *jouissance*, and not its inherent safety” (Hayes, 2012, p. 157).

Psychodynamically, identity formation occurs through “the interplay of psychosexual development, the social mores that accompany sexual morality, and the consequent repression attendant to any particular person’s psychobiography” (Hayes, 2012, p. 151). Bateman and Holmes (1995) state that “the adolescent has to learn how to entrust the other with his anger and sexuality, and not to feel that they will be destructive or rejected” (p. 70). However, HIV with its connection to sexuality “externalises the unconscious phantasy of the ultimate retribution” (Nuttall, 1998, p. 450). In other words, for the participants in this research the possibility of sharing their sexuality and destroying or being rejected by the other is probably all too realistic.

Object relations theory’s basic premise that relationships are key to human development and well-being makes it well equipped to talk about sex because sexual desire is a social phenomenon (Hayes, 2012). Thus, “sexuality seems to have more to do with *relationships* and the *recognition and respect* of our partners than just some base selfish pleasure” (Hayes, 2012, p. 157-158). This is because it is “intersubjective” in the sense that it develops in relationship with an other (Hayes, 2012, p. 151). Originally the other are the parental figures, on which object relations are developed and internalised; however, as previously stated this other can also be any significant person in an individual’s life.

Epstein (1991) demonstrates that object relations theory is particularly valuable in understanding the complexities of sex and sexuality because while social constructionist ideas can explain the broader context of sex, it struggles to account for the internal, psychological factors. The usefulness of object relations theory is that it can account for the social and cultural aspects of sex, while also explaining how individual psyches negotiate and internalise this (Aitken, 2001). This is possible because it “focus[es] on the meanings (conscious and unconscious) that acts – and body parts – have for the person” (Epstein, 1991, p. 852).

### 3.6 Klein, object relations theory and vertically-infected HIV-positive adolescents

Having provided an account of object relations theory, it can be seen that the theory has the ability to understand subjective, internal meanings and realities. It is a psychodynamic theory and as such can interpret the unconscious, such that “the most important, emotionally intricate, lasting, forceful, and ‘driving’” factors of an individual can be understood (Epstein, 1991, p. 842). In addition, its psychodynamic background allows for the interpretation of drawings as projections of the drawer’s internal emotions and unconscious life. Therefore, it is object relations theory’s ability to understand individual “identities as emerging out of a relation between socially constructed categories and intrapsychic and interpersonal experiences” (Epstein, 1991, p. 861), and so its ability to understand the subjective, lived experience, that makes it so useful in understanding the experiences of vertically-infected HIV-positive adolescents.

From the object relations perspective, pathology arises from “the internalisation of disturbed interpersonal relations in the person’s early childhood” (Ivey, 1990, p. 8). In other words, if there is deficient care taking then the child does not experience appropriate relating, and so fails to introject healthily. This results in the individual only being able to relate to others as part objects (Ivey, 1990), and so operate from the paranoid-schizoid position. Alternatively, the individual experiences healthy introjection and operates from the depressive position. This means that the “subject experiences and relates empathetically to the object as a separate, autonomous, complex individual with a unique personality, needs and expectations” (Ivey, 1990, p. 12).

Smiley (2004) found in her psychoanalysis of two HIV-positive men that the HIV confirmed for them that there was something wrong with them and that they were innately bad and unworthy of love. The HIV also moved her clients to a place of insecurity about themselves, their bodies, others, and the world (Smiley, 2004). Smiley (2004) found that trust and intimacy were important themes for her clients, suggesting that the developmental task of intimacy and forming and maintaining relationships with others will be equally difficult for this research's participants.

Thus, if the adolescents are not already operating from a paranoid-schizoid position then their HIV status will probably ensure that they do. This is because Segal (1992) states that "paranoid-schizoid mechanisms and relationships may be used in any situation where life and death anxieties abound" (p. 35) and HIV is heavily linked with ideas about death, annihilation, and disintegration. This will undoubtedly have implications for the developmental task of establishing an identity during adolescence and therefore negotiating intimacy and sexuality.

Lastly, Patton (1998, in Long, 2009) stated that "the HIV positive mother is simultaneously mother and infectious disease" (p. 95). In the same way it could be argued that vertically-infected HIV-positive adolescents are simultaneously sexual adolescent and sexually infectious disease. To hold these two identities together would require the adolescents to operate from the depressive position, which, as stated previously, is unlikely.

### 3.7 Conclusion

This chapter has demonstrated how useful a psychodynamic and object relations framework is in understanding how vertically-infected HIV-positive adolescents' negotiate intimacy, sex and sexuality. This is because the theory provides a framework from which to understand and talk about the role that the unconscious, external reality, internal experiences and perceptions, phantasies and defences play out in an individual's lived experience. This is pivotal to understanding this research's participants, especially given that HIV, intimacy, sex and sexuality are so embedded in the unconscious.

## **CHAPTER 4: Methodology**

### **4.1 Introduction**

This chapter will discuss the methodology of this research. It includes the research design, sampling, procedure, data collection, and the data analysis that was used in the course of the research. It will also discuss the validity of the research and any ethical considerations.

### **4.2 Research design**

Due to the limited research in the field, and the subjective in-depth nature of the research question, this project is qualitative. Camic, Rhodes and Yardley (2003) state that qualitative research is useful for explorative research into areas that have not been extensively researched previously. They state that it is effective at describing within context, is able to explore factors holistically in a way that captures the complexity and subtlety of things, and is able to portray how the topic of research relates to the rest of the world (Camic *et al*, 2003). Thus, qualitative research is capable of providing insight into personal, subjective meaning (Camic *et al*, 2003). Given that the aim of this research was to “describe... in depth and detail, holistically, and in context” (Patton, 2002, p. 55) the lived experience of intimacy, sex and sexuality for the sampled vertically-infected HIV-positive adolescents, it is appropriate that a qualitative research methodology was used.

### **4.3 Sample and sampling procedures**

This research made use of non-probability, purposive sampling. Non-probability sampling, unlike probability sampling, does not make use of random selection and so does not aim to produce generalisable results (Denscombe, 2010; Hall, 2008). This is because the researcher plays a role in the sampling procedure (Denscombe, 2010). Non-probability sampling is useful when researching “an exploratory sample” of a specific group of people with certain experiences (Denscombe, 2010, p. 25).

The research made use of non-probability sampling because the research question was exploratory and qualitative in nature and therefore it was necessary that only vertically-infected HIV-positive adolescents were selected. However, not all vertically-infected HIV-

positive adolescents in South Africa, or even Grahamstown, had an equal chance of being selected. This is because sampling was based on availability and willingness to consent.

Sampling was purposive due to the speciality of the research focus. Participants needed to have been HIV-positive since birth, or soon after, and ideally should have been between the ages of fourteen and nineteen. While two of the participants were within this age bracket, one participant was twenty-one. However, this participant was completing her Grade 12 and so was still developmentally and socially an adolescent (see 2.3.1). The participants' demographics are found in Table 1 below.

**Table 1: Participant demographics**

	<b>Sihle*</b>	<b>Nicky*</b>	<b>Sipho*</b>
<b>Sex</b>	Female	Female	Male
<b>Age</b>	15 years old	21 years old	15 years old
<b>Grade</b>	Special needs school	Grade 12	Grade 8
<b>Socio-economic status</b>	Low economic status	Low economic status	Low economic status
<b>Guardian</b>	Biological mother	Foster mother	Foster mother
<b>Age when found out HIV-positive status</b>	6 years old	13 years old	11 years old
<b>Race</b>	Black	Coloured	Black

\*participants' names are pseudo names

Sampling was initially done, and organised, including helping with the negotiation of consent, through the Raphael Centre, one of the major NGOs that work with HIV/AIDS in Grahamstown (see 4.8; Appendix A & B). However, despite the Raphael Centre's enthusiasm for the research, it proved very difficult to find participants where both the participant and their caregivers gave consent to the research process. It seemed that as soon as caregivers and potential participants found out that the research would involve a discussion around sex, one of them would no longer be prepared to partake in the research. Therefore, only one participant was found through the Raphael Centre and the other two participants were found via snowball sampling. In keeping with the ethics outlined for this research (see 4.8), the

initial negotiation of consent with these later participants was done by their social workers who already knew their status.

#### 4.4 Procedure

At the outset of the research project the Raphael Centre was approached to identify if they had any particular research needs and whether they would be willing to assist in finding research participants. The Raphael Centre immediately identified the sexuality of vertically-infected adolescents as an area of concern with limited research with which to guide them. The Raphael Centre therefore agreed to help facilitate identifying and negotiating consent with potential participants (see 4.8; Appendix A & B).

The research proposal was then written up and submitted to the Rhodes University Psychology Department's 'Research Projects and Ethics Review Committee' (RPERC), the 'Humanities Higher Degree Committee' (HHDC), and the 'Rhodes University Ethical Standards Committee' (ESC). It was passed by all three committees (see Appendix C).

Once ethical clearance was given, the Raphael Centre started approaching potential participants and their caregivers. The Raphael Centre provided basic information about the research and nature of participation (see 4.8). However, only two adolescents and their caregivers were interested enough to meet the principal researcher.

This principal researcher then met with these adolescents and their caregivers. Before consent was asked for, the nature of the research, research questions and participation were fully explained to both adolescents and their guardians (see 4.8; Appendix D). This full disclosure was for ethical reasons to ensure minimum risk and maximum transparency, but also to ensure that participants were willing and able to talk about themselves in relation to the research topic (Taylor & Bogdan, 1984).

It transpired that one adolescent was considering becoming a participant because her caregiver hoped that the research process would make her compliant with her ARVs. This was not the purpose of the research and so it was decided that she would not be a part of the research. She was instead referred to the Rhodes Psychology Clinic for therapy.

There were no reasons to exclude the other adolescent and both she and her caregiver were satisfied with the proposed research process. Therefore, both she and her caregiver consented orally and in writing to the research process, including for the interviews to be video recorded (see Appendix E, F & G). This research participant, who later gave herself the pseudo name of Sihle, was isiXhosa speaking though and so also consented to the use of a translator. Due to the fact that the principal researcher could not pay someone to translate and transcribe, the Rhodes Psychology Honours class were approached for a volunteer. Sanelisiwe Kene volunteered and this researcher then spent time training her and explaining the psychoanalytic research interview. Sanelisiwe also signed an agreement with regards to her role in the research process (see Appendix H). Two interviews, a week apart, were then conducted with Sihle and the translator. The translator then transcribed both interviews.

Given that the Raphael Centre was unable to find participants, snowballing sampling was then utilised. It transpired that a social worker had two clients who were vertically-infected HIV-positive adolescents. As with the Raphael Centre, this social worker approached both participants and their caregivers and broadly explained the research. Both participants and their caregivers then consented for the principal researcher to meet them. This was done in the same fashion as with the Sihle. These participants, who later gave themselves the pseudo names of Nicky and Siphso, and their guardians, consented both orally and in writing to the research process, including for the interviews to be video recorded (see Appendix E, F & G). Nicky was interviewed the next Thursday and Saturday, and Siphso the following two Saturdays.

Nicky was comfortable conducting the interviews in English and so no translator was used. This enabled this principal researcher to transcribe Nicky's interviews. Siphso was more comfortable in isiXhosa and so Sanelisiwe also helped with and transcribed Siphso's interviews.

Once all the verbal content had been transcribed, this principal researcher added the non-verbal indicators to all six interviews. Lastly, the transcripts and drawings were analysed (see 4.6) and the research written up. On the completion of this research the video recordings will be destroyed (see 4.8). Finally, a copy of the full report will be given to the Raphael Centre and limited feedback given to the participants and their caregivers (see 4.8).

## 4.5 Data collection

This research project was multi-methodological in its data collection. It used in-depth, semi-structured individual interviews; and projective drawings. The interviews were semi-structured around the projective drawings, which participants did in the course of each interview. The interviews were video recorded so as to capture dialogue as well as verbal and non-verbal emotional indicators (Bukatko & Daehler, 2004), as was approved in the ethics and consent forms that participants and their caregivers signed (see Appendix C, E, F & G).

Each interview lasted approximately an hour and a half, partly because the drawings took time, and partly to ensure that the desired depth was achieved. Each participant was interviewed twice, one drawing per interview. Interviews were conducted by this researcher, with the idea that her training as a psychologist would foster a containing and judgement-free environment.

### 4.5.1 Semi-structured in-depth interviews

Semi-structured in-depth interviews were used because they are good at capturing the lived, subjective experience (Taylor & Bogdan, 1984), establish rapport, are flexible, “[allow] the interview to go into novel areas, and... produce richer data” (Smith & Osborn, 2008, p. 59). In addition, Smith and Osborn (2008) state that semi-structured interviews are “the exemplary method for [Interpretative Phenomenological Analysis] IPA” (p. 57), the analytic method that was used for this research.

In-depth interviews are “repeated face-to-face encounters... directed toward understanding informants’ perspectives on their lives, experiences, or situations as expressed in their own words” and is more of a conversation between equals than about answering a list of questions (Taylor & Bogdan, 1984, p. 77). Thus in-depth interviewing is good at capturing the lived, subjective experience (Taylor & Bogdan, 1984). In-depth, semi-structured interviews have been successful in research into adolescent sexuality and are found to have the benefit of empowering participants as ‘knowers’ while also helping participants make sense of their own experiences (Striepe & Tolman, 2003).

An interview schedule (see 4.5.5 & 4.5.6) based on the projective drawings was used because interview schedules guide the interviewer as to what information they would like or need, but it simultaneously allows the interviewer to “enter, as far as possible, the [unique] psychological and social world of the respondent” (Smith & Osborn, 2008, p. 59).

#### 4.5.2 Video recording interviews

Sayre and Halling (2007) state that “human communication is a holistic, embodied phenomenon... [such that] what we call verbal communication encompasses a mere fraction of the broad range of human expression” (p. 389). Therefore, in order to capture as much data as possible, and so make the research processes as valuable as possible, the interviews were video recorded for this research.

As with any other kind of recording, video recording can have an impact on the research process and so needs to be considered critically. In addition, participants need to be informed that they will be video recorded (see 4.8), the correct equipment needs to be acquired, and researchers need to ensure that they record correctly (King & Horrock, 2010). This was the case in this research.

King and Horrocks (2010) state that any research that is interested in embodied expression will find video recording helpful. Sayre and Halling (2007) state that “given the embodied nature of human existence, the more the expressive behaviour of the participant is recorded, the more comprehensive the researcher’s access to the lived experience” (p. 390). Thus, the advantage of video recording is that it allows for the capturing of verbal and non-verbal information (King & Horrocks, 2010). It has the ability to capture “gaze, body movement, the relationship of talk to the physical environment and the manipulation of objects” (Liddicoat, 2011, p. 18). Therefore, video recording “gives access to the shared visual space of participants... [and so] captures for the analyst more of what is available to the participants” (Liddicoat, 2011, p. 18). Given the focus on the unconscious and the body in this research, and how much these are communicated non-verbally, video recording thus seemed the most appropriate method of data capture for this research.

However, it is important to remember that video “recordings provide the most accurate version of the data possible, but they do not represent the whole interaction” (Liddicoat,

2011, p. 19). For example, the video recorder is not able to capture factors like transference and countertransference.

One of the disadvantages of video recording is that it is less anonymous than audio recording and so might impact on participants' willingness to consent (Liddicoat, 2011). However, Liddicoat (2011) states that people are more willing to participate if they know that the dissemination of the data will be limited. This was the case with this research's participants.

A second disadvantage is that "transcribing video so you can match the non-verbal with verbal interaction is an extremely arduous process" (King & Horrocks, 2010, p. 46). Sayre and Halling (2007) state that "not only is the task of transcribing audio-visual material overwhelming in terms of time, we also cannot begin to find words to describe the overall embodied expression of an individual" (p. 396). Thus, not only is the data collected by video recording extremely complex, but there is a vast amount of it (Sayre & Halling, 2007). Therefore, there are concerns with the "plausibility and trustworthiness" of the transcription (Sayre & Halling, 2007, p. 391). However, Sayre and Halling (2007) state that with multiple viewings and discussions between researchers or supervisors "transparency and trustworthiness" (p. 397) can be achieved. This was aimed for in this research.

Lastly, as with any kind of recording device, things can go wrong with the recording. For example the microphone might not pick up softly spoken words, the lighting might be off, or action might occur out of the view of the camera (Liddicoat, 2011). In addition, the recording device may impact on the research process by making participants more self-conscious than they would have been otherwise. King and Horrocks (2010) state though that "participants are not necessarily more self-conscious about videoing than audio-recording" (p. 47) and, in their experience, as the interview progresses participants tend to become increasingly less conscious of the camera.

#### 4.5.3 Psychoanalytic research interviews

The psychoanalytic research interview is a meaning-centred research interview that is based on psychoanalytic principles. Cartwright (2004) states that the psychoanalytic research interview "strives to explore intrapsychic processes and unconscious meaning associated with situations, phenomena, or behavioural acts not necessarily linked to the clinical setting" (p.

210). Jervis (2011) further states that the interview “facilitates an exploration of the otherwise inaccessible unconscious communications that exist beneath the surface of interviews, enabling researchers to achieve new levels of understanding” (p. 111).

Psychoanalytic research interviews therefore seek to “uncover unconscious fantasy, object relations, predominant defences, symbolic meaning, and the slippages and transformations that one expects to occur if one is to understand the interview from a psychoanalytic standpoint” (Cartwright, 2004, p. 213). This unconscious is so important because it indicates the kinds of defences that an individual makes use of, and therefore the structure of their object relations (Hollway & Jefferson, 2000). This links to the theoretical framework of Klein and object relations theory.

The psychoanalytic research interview has similarities with the hermeneutic tradition (Cartwright, 2004). This is because psychoanalytic research interviews also acknowledge the circularity of the interview in that “presuppositions, or what is already known, inevitably shape further interpretation” (Cartwright, 2004, p. 214). Within the psychoanalytic research interview, this means that the interviewer will naturally ask questions that lead the participant to reveal their early object relations and unconscious.

The psychoanalytic researcher not only asks specific questions related to the topic of interest, but lets the participant free-associate and takes note of any feelings in either themselves or the participant (Cartwright, 2004; Jervis, 2011). Thus, psychoanalytic research interviews are not particularly structured. This is because structure would lose “a great detail of meaning, context, and detail” (Cartwright, 2004, p. 213). This would undoubtedly result in the loss of the unique, idiosyncratic nature of human psychology and object relations within the interview. Therefore, part of the aim of this research’s interviews was to allow the participants to speak as spontaneously and freely as possible (Smith & Osborn, 2008, p. 61).

Psychoanalytic research interviews make four assumptions. The first is that meaning is co-constructed within the interview setting (Cartwright, 2004). This is because “historical truth is impossible to access after the fact, as it is subject to numerous revisions and interpretations [therefore] it is best viewed as a narrative of the self, a metaphorical elaboration of what was ‘fact’” (Cartwright, 2004, p. 217). Thus, how narratives are constructed becomes as important as the actual content of the narrative. From this perspective, if a certain narrative is repeated a

number of times, then this suggests that it is more consistent and reliable in terms of understanding an individual's intrapsychic makeup (Cartwright, 2004).

The second assumption is that people naturally, unconsciously make associative links in how they talk or tell narratives and that this suggests ways in which the individual is intrapsychically organised (Cartwright, 2004). It is important to remember that the psychoanalytic research is "eliciting the kind of narrative that is not structured according to conscious logic, but according to unconscious logic; that is, associations follow pathways defined by emotional motivations, rather than rational intentions" (Hollway & Jefferson, 2000, p. 37). Therefore, it is important to create a space in which participants feel comfortable and contained enough to freely construct narratives (Jervis, 2011).

The third assumption is that the context of the interview is extremely influential in determining the interview (Cartwright, 2004). This is referring to the multitude of "internal and external" factors that impact "on the way an individual communicates and how the communication is understood" (Cartwright, 2004, p. 220). Therefore, as with the hermeneutic tradition, when analysing and interpreting any interview, it is fundamental that the interview context and the interview as a whole be taken into consideration (Cartwright, 2004). This includes the role of the interviewer and translator (Cartwright, 2004).

The fourth assumption is that transference and counter-transference are helpful in gathering unconscious information about participants (Cartwright, 2004; Jervis, 2011). Hollway and Jefferson (2000) state that "as researchers, therefore, we cannot be detached but must examine our subjective involvement because it will help to shape the way in which we interpret the interview data" (p. 33). However, preconceptions and fears may impact the process and so it is essential that transference and counter-transference issues are considered reflexively to eliminate as much bias as possible (Cartwright, 2004).

While positivist thinkers have significant concerns around how scientific such psychoanalytic research interviews are, even they acknowledge "its potential for personal change as well as its contributions to knowledge about the human condition" (Kvale, 1996, p. 78). Therefore, while the method's first priority is to gain knowledge, an often unavoidable benefit is that it can provide the participant with a psychological space that they would not have had otherwise and so possibly bring about some positive change in their lives.

#### 4.5.4 Projective techniques within the research context

Patton (2002) states that data collection has been done creatively, based on projective techniques eliciting responses to “something other than a question” (p. 396), by a number of qualitative researchers. Drawing can be helpful for “participants [to] collect their thoughts and explain how they see a concept or idea” (Kruegar & Casey, 2000, p. 53). This is especially the case when working with young participants (Kruegar & Casey, 2000; Patton, 2002). It is also important given the personal, sensitive nature of the interview topics. Thus two projectives were collected in the course of this research: a body map drawing and a drawing of what the participants conceive sexuality to look like.

Piko and Bak (2006) state that drawings have been used to gain insight into the lives of children. The drawings in this project were specifically elicited to gather particular information related to the sexuality and sense of self of the adolescents in this project. These drawings contain projective information and so can be analysed as projectives because people naturally demonstrate in their drawings, often unconsciously, their perceptions of themselves and of the world, whether they mean to or not (DiLeo, 1973; Mortensen, 1991). DiLeo (1983) states: “it is my conviction that each drawing is a reflection of the personality of its maker; that it expresses affective aspects of the personality as well as cognition; that it is telling... more about the artist than about the object portrayed” (p. 60). In addition, Mortensen (1991) says that “drawing is seen as a reflection of the [person’s] personality, of his [sic] subjective experience of what it feels like from the inside to be a human being” (p. 3).

There is a clear link between what or how people draw and their emotional well-being. Thus, drawings have been used “as aids in the diagnosis of emotional and behavioural problems and also in therapy” (Cox & Catte, 2000, p. 301). Therefore, it was appropriate that the drawings collected in the course of this research were analysed as projectives as they provided access into the emotional, intrapsychic experience of the participants that they might not otherwise have been able to articulate.

#### 4.5.5 Interview 1

The first interview focused on gathering information pertaining to the participants’ overall sense of self in relation to their external reality and others. This can be gathered from a

drawing of the self because the self is a reflection of the introjection of others (Thomas, 1996). Participants were asked to draw an outline of their bodies using a black Koki pen on an A3 piece of paper, and then to draw onto their body maps their different roles, identities, and important parts of themselves. Participants had at their disposal watercolour pencil crayons, pastels, crayons, charcoal, pencils, and magazines with scissors and glue. Due to the fact that participants were aware that the research was looking at HIV-positive adolescents and how they negotiate HIV, their emerging sexuality, and adolescence, it was expected that the participants would probably draw these three identities.

The interview was then structured around what participants drew and their relationship with the different parts of themselves and others. Questions focused on what each role and part of the self meant to the participants, the emotions that were associated with each, and how sex and HIV impact on the participants' sense of self. Thus, the relationship that the participants have with themselves and others was elicited. It was also discussed how all the different roles, selves and emotions come together into one body.

Thus the interview question themes were:

- 1) What their different selves are
  - a. What their relationship is to their different selves
- 2) What their different roles are
  - a. What their relationship is to their different roles
- 3) What their HIV self means to them:
  - a. How they feel about this self
- 4) What their adolescent self means to them:
  - a. How they feel about this self
- 5) What their sexual identity means to the participants:
  - a. How they feel about this identity
- 6) How these different roles and selves fit together

#### 4.5.6 Interview 2

The second interview focused on getting information pertaining to the participants' sexual identities. This topic was interviewed about second, once some rapport had been established, because of its personal and sensitive nature. Participants were given an A3 piece of paper and

asked to draw what they conceive sexuality to look like. This could be as literal or as abstract as the participants liked. The idea of drawing their sexuality was to elicit the factors that are barriers or facilitators to sexuality and intimacy for the participants, and their emotions related to this. Participants had at their disposal watercolour pencil crayons, pastels, crayons, charcoal, pencils, and magazines with scissors and glue.

Again, the interview was structured around what participants drew. Questions focused on what sexuality and intimacy meant to the participants, what they hope for, how disclosure impacts on sexuality and intimacy, and how the participants feel about their sexuality and desire to have sex.

Thus the interview themes were:

- 1) What sexuality looks like
- 2) What sexuality does
- 3) What sexuality wants
- 4) What helps sexuality
- 5) What is a barrier to sexuality
- 6) Does sexuality want something different to what they want
- 7) How sexuality makes the participants feel:
  - a. How the participants feel about the fact that they want to have sex
- 8) What being intimate means to the participants
  - a. What a good or bad relationship looks like
- 9) What the participants hope for the future with regards to their sexuality and intimacy

Lastly, the participants were also asked if there was anything else that they would like to add, and to reflect on how they had found the two interviews.

#### 4.6 Data analysis

The video recordings of the interviews were transcribed and translated into English. The videos were analysed for verbal and non-verbal emotional indicators based on psychodynamic principles as related to the object relations framework. The body maps and sexuality drawings were analysed for projective indicators, emotional and unconscious, that

suggested how participants experience intimacy, sex and sexuality intrapsychically. This was done using object relations theory within the context of what the participants said about the drawings.

Cartwright (2004, p. 211) states that the psychoanalytic research interview should be analysed in the following manner:

- (1) The search for core narratives while exploring the interview in its entirety;
- (2) Matching narratives with initial transference-countertransference impressions; and
- (3) Tracking key identifications and object relations within dominant interview narratives.

This is supported by Jervis (2011) who states that researchers should thoroughly immerse themselves in the data and then reflect “upon each interview, considering not only what was said but also, as in psychoanalysis, what might have been unconsciously imparted” (p. 112-113). This includes the interviewer’s and the participants’ emotions, transference and countertransference (Jervis, 2011).

While this research project conducted psychoanalytic research interviews, they were not analysed purely as Cartwright suggests. This is because IPA was used to make sense of the multiple sources of data collected as a whole. IPA is a “qualitative research approach committed to the examination of how people make sense of their major life experiences” (Smith, Flowers, & Larkin, 2009, p. 1). It is phenomenological, hermeneutic and idiographic and so aims to identify an individual’s unique, personal experiences and perceptions (Shaw, 2010; Smith & Osborn, 2008). Shaw (2010) states that from an IPA perspective “although we accept that events ‘actually exist’ in reality, we realise that our only access to those events is through a particular lens” (p. 178). This links well with this project’s theoretical underpinning of object relations theory.

IPA was used because it is a well-established method of analysis that “has a theoretical commitment to the person as a cognitive, linguistic, affective, physical being and assumes a chain of connection between people’s talk and their thinking and emotional state” (Smith & Osborn, 2008, p. 54). In other words, it seeks to capture how people experience and understand the personal and social aspects of their lives (Smith & Osborn, 2008). This is in a

very isolated, context specific sense in that it seeks “to understand people’s experiences at a particular point in history, a particular time in the life, in that social, cultural, political and economic context” (Shaw, 2010, p. 178).

In addition, IPA is useful for conducting in-depth analysis to understand people’s deep, subjective experiences of themselves and the world, especially when little is known about the research topic (Smith *et al*, 2009; Smith & Osborn, 2008). This is because it is “concerned with complexity, process or novelty” (Smith & Osborn, 2008, p. 55). This links well with this project’s data collection method of semi-structured in-depth interviews (Smith *et al*, 2009; Smith & Osborn, 2008).

As can be seen, there are a number of similarities between how psychoanalytic research interviews are conducted and how IPA is analysed. Both methods require an immersion in the data, both look for themes or repeating narratives, and both try to make sense of in-depth personal experience. Therefore, it is argued that these methods link together in a useable way for the purpose of this research project. The additional input that the psychodynamic method of analysis, as well as the theoretical grounding of this project, added to IPA analysis was to ensure a focus on transference and counter-transference, in addition to the early object relations and intrapsychic world of the research participants.

In the analysis of the transference and counter-transference it is important to be aware that the feeling states during the interview may still be present during the analysis process and so bias interpretation (Cartwright, 2004). Unfortunately, this cannot be avoided. However, “acknowledgement allows for some degree of control over the process of contextualising interpretations in the interview” (Cartwright, 2004, p. 223). Therefore, Cartwright (2004) argues that “reflecting on feeling states should thus become an integral part of understanding how psychoanalytic knowledge is co-constructed” (p. 223).

The transcripts from the interviews were therefore analysed using both deductive and inductive IPA, bearing in mind the drawings that were being spoken about and the psychodynamic theoretical framework of this project. IPA was done according to the suggestions outlined by Smith and Osborn (2008, p. 67 - 76): (a) read and immerse into one transcript to identify themes, (b) cluster connected themes together, (c) repeat (a) and (b) with other cases, (d) bring the themes from all the different cases together and cluster based on

frequency, richness in transcripts, and how they enlighten other aspects of the account, and lastly (e) write all the themes into a narrative account.

This meant that this researcher immersed herself into Sihle's video recording and transcript; wrote anything that seemed important in the left hand side of the transcript; and then wrote themes in the right hand side of the transcript (a). Secondly, the themes from Sihle's transcripts were clustered together in a meaningful way (b). The same was then done for Nicky and Sipho's transcripts (c), all the time looking for themes that were both similar and dissimilar to Sihle's themes. Next, Sihle, Nicky and Sipho's themes were brought together (d). Due to the large amount of data, this was organised and selected based on the richness of themes and which themes would best answer the research question. Lastly, the themes were written into a narrative account (e) (see Chapter 5). In this way this research attempted to make sense of how the research "participants [were] trying to make sense of their world" (Smith & Osborn, 2008, p. 54).

#### 4.7 Validity of research

Qualitative research necessarily raises questions of reliability and validity (Van der Riet & Durrheim, 2006). Reliability is "the consistency or stability of a measure" (Cozby, 2005, p. 92). Durrheim and Painter (2006) state that reliability is whether the research can be repeated. Durrheim and Painter (2006) define validity as "the degree to which a measure does what it is intended to" (p. 147). Durrheim (1999) distinguishes between two kinds of validity: internal validity and external validity. External validity is concerned with whether the results can be generalised or not (Durrheim, 1999). Internal validity is concerned with whether "any results arrived at are sustained by the design itself, and cannot be explained by alternative considerations" (Durrheim, 1999, p. 313).

However, the control required in attaining reliability and validity is impossible in qualitative research (Ankomah & Ford, 1994). The terms 'validity' and 'reliability' bring implications and expectations that cannot be realised in qualitative work. Burns (1985 in Knoff & Prout, 1985) points out that "if a relatively simple task such as validating the perception of the objective moon takes thousands of human years, the validity of what we perceive in the human mind may take longer" (p. xii). From this point of view it does not seem rational to

expect research about something as subjective as someone's experiences, emotions and perceptions to be completely reliable and valid.

Therefore, qualitative approach has other ways of attempting to ensure quality. Babbie and Mouton (2005) prefer the terms 'credibility' and 'transferability', instead of validity and reliability, when talking about qualitative work. In other words, 'credibility' and 'transferability' are qualitative research's adaption of 'reliability' and 'validity', and as such are not exactly the same as 'reliability' and 'validity'.

Qualitative research thus aims for trustworthiness, which requires credibility, transferability, dependability, and confirmability (Babbie & Mouton, 2005). Credibility is the "compatibility between the constructed realities that exist in the minds of the respondents and those that are attributed to them" (Babbie & Mouton, 2005, pp. 277). Interpretations were supported both by what the participant said and drew. This was ensured by the project supervisor re-checking interpretations for their plausibility. Transferability is "the extent to which the findings can be applied to other contexts or with other respondents" (Babbie & Mouton, 2005, p. 277). It is the responsibility of whoever may use this research to ensure that it applies to their context. Dependability is that the findings would be repeated with similar participants in a similar context, and confirmability is that "the findings are the product of the focus of the inquiry and not of the biases of the researcher" (Babbie & Mouton, 2005, p. 278). Dependability and confirmability were ensured by this researcher being as reflective as possible about her own intrapsychic processes and working closely with the research supervisor.

Psychoanalytic research interviews pose a particular threat for reliability and validity. This is because an interview is not a psychoanalytic, clinical setting, and so the application of psychoanalytic techniques should be done critically (Cartwright, 2004). In addition, "the method of enquiry is not explicated in a way that would allow objective scrutiny" (Cartwright, 2004, p. 212). This is because the interviewer, due to transference and counter-transference dynamics, is so much a part of the process (Cartwright, 2004). The same can be said for the translator. However, the tradition of being personally reflective about one's own intrapsychic processes as a psychodynamic therapist lends itself to ensuring that the same is done within the interview context and so reduces bias. In addition, with regards to applying psychoanalytic techniques to the interview context, Cartwright (2004) states that "the narrative tradition in psychoanalysis places considerable emphasis on understanding the

processes that lie behind the development of meaning and interpretation and thus readily lends itself to the concerns of understanding the interview” (p. 217). Psychoanalytic research interviews are thus an appropriate method of research as long as they are used reflexively with the normal aim for credibility, transferability, dependability, and confirmability.

#### 4.8 Ethical considerations

This research project aimed to research how vertically-infected HIV-positive adolescents experience the emerging developmental tasks of intimacy, sex and sexuality in relation to their HIV status. Therefore it required engaging with vulnerable participants about a sensitive, potentially embarrassing, topic. This means that this research was a code red project. However, there was a favourable risk-benefit ratio (Emanuel, Wendler, & Grady, 2000) for a number of reasons. This was because it was conducted so as to guard against any risk and possibly actually bring about some benefit to participants, as described below.

Firstly, the risk to the participants was greatly reduced due to the involvement and guidance of the Raphael Centre and relevant social worker. They approached potential participants, and facilitated the explanation of the research with guardians and participants, as well as the negotiation of consent and confidentiality. With regards to approaching potential participants, it is significant that this was done by the Raphael Centre and social worker because they already knew adolescents’ statuses, had a relationship with the participants, and had normalised HIV and discussions around sex for these adolescents. This means that participant recruitment posed minimal risk to participants. Evidence of this is that so many potential participants felt safe enough to choose not to participate.

The Raphael Centre was willing to act as a gatekeeper because when this researcher, who worked at the Raphael Centre during her Undergraduate Degree, approached the Raphael Centre with the idea of doing research with HIV-positive children, they immediately identified the sexuality of HIV-positive adolescents as an area with which they are struggling. In this way this research was in response to requests from HIV-positive adolescents themselves for help from the Raphael Centre with regards to their awakening sexualities. Therefore, although the participants were vulnerable, they themselves had requested help in this area.

Secondly, as stated previously, there is extremely limited research into HIV-positive adolescents, particularly into their in-depth lived experiences, and this lack of research itself is becoming unethical. Without research, without anyone giving these adolescents a voice, support and interventions for these adolescents are not going to be as effective as they could be. This can be seen in the Raphael Centre's support of this research: they have a growing HIV-positive adolescent demographic but not the guidelines on how best to cope with it. This is of great concern, especially given that the demographic is growing. Emanuel *et al* (2000) state that in order for research to be ethical it has to be valuable and knowledge that is needed, which is the case with this research.

Thirdly, potential participants and their parents or guardians had the nature of the research and participation process fully explained before they were asked to consent. It was made clear that participation was voluntary, that there would be no negative consequences if they did not participate, and that they would be able to withdraw from the project should they so choose. Potential participants were also informed that they could choose not to answer questions if they were uncomfortable doing so. Consent was sought to video record the interviews but participants were informed that the video tapes and any identifying information would be destroyed once the relevant information has been transcribed and documented, and that no one except the principal research, supervisor and translator would see them. While this documentation took place, the videos and identifying information were kept in the researcher's locked cabinet in her office with her other clinical material to ensure confidentiality. Only the transcripts and drawings, without any identifying information, will be kept as the property of Rhodes University for possible future research. Due to the fact that participants were minors, consent was asked for from participants' guardians, as well as the participants themselves, orally and in writing (see Appendix E, F & G).

Therefore, participants' anonymity and confidentiality were protected in every possible way, while still ensuring that the research was as rich and accurate as possible and so worth the potential risks that may have been incurred. This research report, which contains no identifying information, will be made available to the Raphael Centre. Readers who know participants well may be able to identify participants from the research report. However, the Director of the Raphael Centre highly values the confidentiality of participants and so will not share the report with anyone who knows the participants well enough to be able to do this. Participants were informed of this. In addition, some feedback will be given to the

participants and their guardians. The full research report will not be made available to guardians because this could compromise the participants' confidentiality.

Fourthly, with regards to the actual research process, this researcher, who conducted the interviews, has previous experience with the particular risk factors involved in this research because she is training to be a psychologist and so was comfortable with any psychological vulnerability that occurred. She also has significant work experience working and volunteering with children, including at the Raphael Centre. In addition, Ms Patel who is a registered psychologist supervised the project. Therefore, any psychological distress that occurred was contained as soon as it arose in the interviews. When the interview process revealed that a participant was in need of a therapeutic space, which occurred for all three participants, it was offered that they could be referred to the Rhodes Psychology Clinic for therapy. However, none of the participants chose to engage in a therapeutic process. One participant did want to join a support group at the Raphael Centre for HIV-positive adolescents though.

Lastly, the participants were expected to experience benefit from the research process. Striepe and Tolman (2003) found that the process of in-depth interviews in their research about adolescent sexuality had the benefit of letting each participant tell their own story, empowered participants as 'knowers', and often helped participants make sense of their own experiences by having to explain it to someone else. Thus, while this research did not claim to be able to produce answers for these adolescents, the research process and discussions may have been of some use to the participants. At the very minimum, this research provided participants with a space to talk about sensitive issues in a safe and contained way. It provided the opportunity for participants to have their experiences acknowledged and validated, which can be extremely empowering. This is supported by Fernet *et al* (2007; see 2.4.2).

Therefore, while this research was a code red project, great caution was taken to reduce risk and ensure that it was conducted in as ethical and protective a manner as possible. In addition, it was wanted by the gatekeepers and the participants themselves. Lastly, the participants probably benefited from, and valued, the opportunity to talk and be listened to in such a containing way.

#### 4.9 Conclusion

This chapter has described the methodology of this research project. It has used a qualitative research design and non-probability, purposive and snowball sampling. Data collection involved two in-depth, semi-structured psychoanalytic research interviews centred on projective drawings related to identity in the first interview and sexuality in the second. Data analysis was based on IPA but took the psychodynamic framework for this research into account. Lastly, the validity of qualitative research and the measures that were taken to ensure that the research was ethical were discussed.

## **CHAPTER 5: Findings and Discussion**

### **5.1 Introduction**

This chapter will discuss the findings of the research interviews that were conducted. It will aim to answer this research project's research question about how vertically-infected HIV-positive adolescents experience intimacy, sex and sexuality in relation to their HIV status. In this regard, three major themes have been identified: the experience of intimacy, self, and sex and sexuality.

### **5.2 The experience of intimacy: “*They give me hope even though I won't be alright*”**

Intimacy is defined as the ability to form and maintain close interpersonal relationships with others (Erikson, 1950). This refers to both platonic and sexual relationships. The ability to form and maintain intimate relationships is informed by dominant object relation experiences (Lemma, 2003), as these inform how an individual experiences and perceives others.

Kelly *et al* (2008) state that HIV complicates how people who are HIV-positive feel in relationship to others. Therefore, in order to understand how the vertically-infected HIV-positive adolescents in this research experience intimacy it is necessary to understand the adolescents' dominant attachment figures and how this has impacted on the adolescents' perception of the world and others in relation to their HIV-status. This theme thus has four sub-themes: dominant attachment figures, the badness and untrustworthiness of others and the world, the use of boundaries to make participants feel safe, and the participants' desire for intimacy. The theme of sexual intimacy will be discussed later in how participants experience sex and sexuality (see 5.4).

#### **5.2.1 Dominant attachment figures**

Literature states that the early relationship between mother and child is critical in shaping an individual's personality (Ivey, 1990; Lemma, 2003). Therefore, the early interaction that the vertically-infected HIV-positive adolescents had with their (HIV-positive) mothers is fundamental to how the participants currently negotiate their relationship with others.

All three research participants narrated themselves as not being understood by others. This is possibly common in the lived experience of being HIV-positive as people are fearful of presenting themselves in a way in which they can be understood owing to concerns about HIV-related stigma (Rohleder & Gibson, 2006). In this research the participants have experienced a number of relationships in which they are not known by the other. Nicky stated:

- L: So when people tell you that you'll be ok  
N: Ya and –  
L: You don't believe them  
N: Others they give hopeful that no you must eat this in order to be ok, even though...  
L: You will never be ok  
N: *(Nicky's gestures suggest that others think that they are giving her hope but that are clearly not – almost lying to her; Nicky is very heavy/sad/hopeless)* Ya... they just... give me hope, even though I won't be... (Nicky, 1, p. 77)
- N: Ya, she [Nicky's foster mother] stopped me [committing suicide]... and we talk about that. She said "no, it's not right. Life has its obstacles, ya. I must learn, to move... forward"  
L: What did you think of that?  
N: Ah, I didn't, I didn't take her serious that because... life *(Nicky laughs)* being HIV is different (Nicky, 1, p. 78)

Nicky feels different to others because of her HIV-positive status. However, this sense of differentness is problematic because others are unable to recognise it. While Nicky feels that she will "never be ok" others are unwilling to acknowledge this. Nicky's foster mother is unable or unwilling to acknowledge how difficult Nicky's life is for her living with HIV. In other words, even those who do know about Nicky's HIV-positive status are unwilling to be with her in her perceived realities of being HIV-positive. The alternative to this blindness to HIV is that HIV is all that people see, such that others become overly focused on the participants taking care of themselves, being responsible and not infecting anyone else. This can also be seen with Siphon and Sihle. Both extremes result in the participants not experiencing themselves as understood by others. Thus, there is an incongruity of experience between the participants' self-perceptions and how others relate to the participants.

This suggests that this research's participants are not experiencing what Epstein (1991) describes as human beings' most fundamental need: connection with others. This is problematic for three reasons according to object relations theory. Firstly, being understood by an other is necessary in order for an individual to differentiate between

external and internal reality (Winnicott, 1971). Secondly, it means that there is no meeting place or transitional space (Aitken, 2001; Ivey, 1990) between the participants and others. This is problematic because transitional space is necessary for symbol formation and creative symbolism (Ivey, 1990) and for developing a sense of self (Thomas, 1996).

People only come to know themselves through experiencing others knowing them (Ivey, 1990). This is important because if an individual does not have a sense of self it impacts negatively on their ability to form intimate relationships (Erikson, 1950). Sihle stated:

*(Sihle speaks in a soft voice and runs her hand down the length of the roll) I try for my mom [...] And friends (Sihle, 1, p. 46)*

It [taking part in this research] helped so I can also live—people also know who I am. So I can live without other people then (Sihle, 2, p. 51)

Sihle tries for her mom and friends, rather than for herself. She liked participating in this research because it meant that others came to know her. Sihle seems to experience herself as unknown to others, therefore unknown to herself, and as such is only able to live through others. These narratives suggest that Sihle has not introjected a sense of self from others (Ivey, 1990) and as such has an impoverished self. This impoverished self seems to be the case with all three participants as demonstrated by their human figure drawings in Interview 1 (see Appendix I, K & M). This will be discussed in detail later (see 5.3.2).

Thus the participants' experiences with the dominant attachment figures in their lives have resulted in the participants not experiencing being understood by an other. Others do not know the adolescents' HIV-positive status, are unable to acknowledge the difficulties of being HIV-positive, or only see the HIV. It therefore would appear that each participant has an impoverished sense of self. This makes the experience of intimacy extremely challenging as participants present a self based on what participants think that the other needs rather than just being able to be themselves.

#### 5.2.1.1 Early attachment figures

The participants' early attachment figures are crucial because they represent the first object relations that were created for the research's participants (Lemma, 2003). As a result, the early attachment figures have a pervasive impact on the adolescents' personality development

and experience of intimacy (Ivey, 1990; Lemma, 2003). Early attachment figures are particularly interesting for vertically-infected HIV-positive adolescents because by definition their primary attachment figures, their mothers, are sick with HIV (Long, 2009). This necessarily impacts, not necessarily negatively though, on the mother's ability to care for, and the quality of relationship that they are able to establish with, their child (Long, 2009).

All three participants linked their HIV status with their mothers. Long (1990) describes the "guilt of being an infective mother" (p. 166). The psychological effects of being 'an infected child' however are interesting because a mother is someone who is supposed to protect her child, not make her child sick (Long, 2009). Therefore, the infant's unconscious phantasy of being sadistically harmed by their mother (Segal, 1992) has become an external reality (St. Clair, 2000). Nicky and Sihle stated:

*(Sihle looks down... looks up again and starts rolling the paper again... completely finishes rolling it and then taps it on her hand as she talks) I started [treatment] when I was young because my mom—I didn't know—I was born with it (Sihle, 1, p. 27)*

N: I just hate them [her parents] sometimes  
L: You hate them?  
N: Ya  
L: Because they made or sick or what...?  
N: Ya because they made me sick and, and they just died and they make my life –  
L: Just left you  
N: Ya, my life miserable (Nicky, 1, p. 65)

Sihle initially pairs her HIV status with her mother. She then however defends against this knowledge by stating "I don't know" and instead states that she was born with HIV. Nicky alternatively, displays significant anger towards her biological parents. The emphasis on "just died" in Nicky's quote suggests that for Nicky, the most traumatic factor is her parents' death and abandonment of her, rather than her parents making her sick. This is similar to Siphó's experience. In other words, the externalisation of the phantasy (Segal, 1992) of abandonment is worse than the externalisation of the phantasy of being harmed.

The difference in the responses from Sihle, Nicky and Siphó can be attributed to the fact that Sihle's mother is still alive while Nicky and Siphó's parents have passed away so that Nicky and Siphó currently live with foster mothers. The passing away of parents is common given the extent of the HIV pandemic (Chigwedere *et al*, 2008; UNAIDS, 2012a; see 1.1). Nicky and Siphó stated:

*(Nicky shaking her head)* Yoah, I don't know my her at all. She passed away when I was... two years [...] Ya... I only know my father... through a photo (Nicky, 1, p. 57)

So my, my, my foster mother is my, my dad, my dad's aunt [...] *(Last sentence very quiet)* Ya. So they had a fight. Then, and I was, I was ill, and my grandmother was, was an, an alco-, an alco, – an alcoholic, then, ah she didn't took me to treatment, and she didn't give me that special treatment... Then the social worker took me away. (Nicky, 1, p. 59)

[Talking about his current foster home] *(Moves back in his chair, fidgets, brushes his face and moves his legs)* maybe no one hits each other, there's no...there's no saying maybe—there's no maybe...they...drink and swear at each other. We just live together happily (Sipho, 1, p. 9)

Nicky lost her primary attachment figure, her mother, when she was two years old, but probably younger because her mother would have been sick and unable to take care of her. Nicky does not remember her father. After her mother passed away Nicky lived with her grandmother. However, this was not a good relationship as Nicky was removed due to neglect. Sipho has had a similar experience to Nicky where his mother passed away when he was very young and his father 'threw him away' (Sipho, 2, p. 17) to his foster mother in Grahamstown when Sipho was in Grade R. Implied in Sipho's narrative above is that Sipho has previously experienced a family where domestic violence and alcohol abuse were present. He confirms this later by stating that his mother used to drink alcohol. These narratives provide a sense that for Nicky and Sipho there is a gaping hole where their parents are concerned. The phantasies of abandonment (Bateman & Holmes, 1995) have become a permanent external reality for Nicky and Sipho.

Given that the infant uses the normally temporary experience of abandonment to develop the feeling of hate (Bateman & Holmes, 1995), it is consistent that Nicky and Sipho express significant anger and blame towards their parents:

*(Sipho shifts in his chair and wipes his face; fiddles with his earphones)* ...if she [Sipho's mother]...if she didn't drink (*drag*)...or...sleep with men she wouldn't have gotten HIV (Sipho, 1, p. 38)

Maybe, ya, maybe I shouldn't have been infected if they [her parents] had taken responsibility from the first place (Nicky, 1, p. 66)

Sipho's use of the words "didn't drink or sleep with men" is reminiscent of the metaphor of HIV as sinful and promiscuous (Hayes, 2012; Sontag, 1991, in Rohleder & Gibson, 2006). Sipho and Nicky both believe that if their parents had acted differently their parents would

not have become HIV-positive, and by implication Siphó and Nicky would not have either. Thus, from Nicky and Siphó's perspectives their parents failed to be responsible and look after their children. Both quotes imply the internalisation of the idea that to acquire HIV one must have been irresponsible and, as such, people are to be blamed for their infection (Deacon et al., 2009). Thus, Siphó and Nicky seem to be making use of HIV-related stigma to further split off their parents as bad objects. This is a psychological defence (Lemma, 2003) possibly against the pain of being abandoned.

Sihle on the other hand is unable or unwilling to acknowledge the feelings associated with the fact that her mother is the person who made her sick. Sihle described having a good relationship with her mother such that her mother talks and laughs with her to help her forget about things when they are difficult (Sihle, 1, p. 47). Sihle seems to have cut off any negative feelings that she might have towards her mother (Bateman & Holmes, 1995). This psychological defence (Lemma, 2003) enables Sihle to retain a sense of her mother as good. This is important because Sihle is the only participant whose primary attachment figure has not passed away and abandoned her. As such, Sihle is the only participant who has a positive HIV-positive role model. However, Sihle also stated:

- L: ok...do you know why your mom tells you that? Why—what—why do you think is the reason your mom is saying that you must tell him about it [her HIV status]?
- T: do you know why your mom tells you that?
- S: yes
- T: why does she say it?
- S: because she says you have to tell a person early on so that they can use a condom. And end up saving themselves (Sihle, 2, p. 40)

Sihle's mother has instructed Sihle to disclose her HIV-positive status to her potential sexual partners. The phrase "saving themselves" implies though that Sihle is dangerous. Therefore, in trying to encourage Sihle to practice safe sex, a concern that dominates literature (Hayes, 2012), Sihle's mother has implied that Sihle is something that people need to be protected from. Sihle seems to have internalised this sense of herself as dangerous into her enduring self-concept (Ivey, 1990; Klein, 1952). In this way Sihle has introjected her mother's badness, thus further ensuring that her mother remains a good object (Ivey, 1990). It can be said that even though Sihle's mother did not permanently abandon Sihle, she has not been an entirely positive attachment figure.

The research participants' experiences of their early dominant attachment figures are fundamental because people internalise external experiences and take them in to mean something about themselves (Ivey, 1990; Klein, 1952; Rohleder & Gibson, 2006). Nicky's and Sipho's parents' deaths are problematic because the phantasy left behind in each is that the self is abandoned and therefore possibly unlovable and bad. In addition, others are perceived as abandoning and not to be trusted to be constant. Sihle's phantasy is that the self is dangerous and therefore possibly that she too is unlovable and bad.

It is thus clear that all three participants have linked their HIV-positive status with their mothers. This means that the one person who was supposed to take care of the adolescents and keep the adolescents safe failed to do this. Sihle's mother has not permanently abandoned her though and so Sihle has cut off the implications of her mother infecting her. This is because it enables her mother to remain an idealised good object. However, Sipho and Nicky are both in touch with their anger towards their parents for having infected and abandoned them. Sipho's and Nicky's primary attachment figures have become split-off, hated, bad objects. It would seem that the resultant phantasy from all three participants' experiences is that the self is unlovable and bad. Therefore it is likely that the participants do not expect others to want to or to maintain intimate relationships with the participants. This will impact negatively on the participants' experience of intimacy.

#### 5.2.1.2 Current attachment figures

In line with the fluid nature of the constant negotiation of boundaries within the object relations framework (Aitken, 2001), Andersen and Przybylinski (2012) argue that the self is constructed in relationship with significant others throughout a person's life. This indicates that the research participants' negotiation and experience of intimacy will be impacted on by both their early attachment figures and their current attachment figures. These current attachment figures include the participants' foster mothers and peers. It seems that the participants' current attachment figures serve to confirm their early attachment experiences, which in turn challenges the participants' experience of intimacy.

Nicky's and Sipho's current attachment figures were articulated by them as a vast improvement on their previous attachment figures. Nicky stated:

- N: Yoah, we [Nicky's foster mother and her] are so close (*smiling*) [...] We share e- (*Nicky starts laughing*), we share e-jokes together [...] We, we understand each other... even if, if I'm not.. right... she understands that I'm not right, yes she asks me what's wrong, ya [...] I talk wi- I talk her [...] She's like my friend [...] Ya, most of the time she likes to dance (*Nicky starts laughing and Lindsay joins her*). Ya, we laugh
- L: Do you dance with her?
- N: (*Lindsay laughing*) No, I don't because no I like to laugh (*Nicky and Lindsay laugh together*). [...] Ya, even if we go to town... she, she hold my hand (Nicky, 1, p. 55 – 56)

Ah... I gave my mum a thank, a big thank [...] (*Very moving to listen to*) The way they, they accept me that I'm... ya, I'm their sister... and my mum, everything that she did for me, took me on treatment... go up and down with me when I was ill, took me to PE hospital when I was ill, be there for me [...] Ya. And I was, I, told her that, if it wasn't for her, maybe I, maybe others would, maybe others would said things about me, like "there was a kid who was like dadadada" and then I was already passed away. Ya. (Nicky, 1, p. 61)

Nicky's foster mother is there for Nicky even when Nicky is not "right". This represents an unconditionally caring, loving and fun relationship. Nicky's foster mother took care of Nicky when she was ill and so literally gave Nicky life like a real mother. This stands in stark contrast to how Nicky feels about her biological mother. Nicky (1, p. 32) states that the support of her family is what gets her through the difficulties of being HIV-positive. Siphos does not describe in any detail a close relationship with his foster mother but mentions his grandmother, who also lives with the family. He states that it is his grandmother who, with her pension, feeds and takes care of him (Siphos, 1, p. 20).

Siphos and Nicky's current attachments make the case for disconfirming their early object relations based on their primary attachments' abandonment (Segal, 1992). This is because their current attachments are narrated more positively and so allow for the participants to create a more positive introject of themselves, others and intimacy (Ivey, 1990). However, these current attachments can never take away the pain of the loss of their primary attachments. This is because experiences remain in the unconscious (Freud, 1905; Likierman & Urban, 1999). Given that Nicky periodically makes use of whole object relating, the ability to hold that something is both good and bad (Hinshelwood, 1991), it is likely that Nicky's relationship with her foster mother has at times enabled Nicky to move away from experiencing persecutory anxieties (Ivey, 1990; Lemma, 2003). However, the themes of death and stress associated with her HIV status often pull Nicky back into these anxieties of annihilation (Segal, 1992). This has been noted in other literature concerning HIV-positive populations (Nuttall, 1998; Smiley, 2004).

However, despite Siphon and Nicky's improved attachment figures, it would appear that Nicky and Siphon's attachments are still challenging. Firstly, both participants struggle to have a sense of being understood by their caregivers. Secondly, the current attachment figures betrayed the participants by not immediately disclosing the participants' HIV-status, and therefore became untrustworthy. Nicky was initially told that she had asthma (Nicky, 1, p. 67). Siphon asserted that his foster mother was told that he was HIV-positive when they went to fetch Siphon's treatment and she then told Siphon when they got home. However, in order for Siphon to have been taken to the clinic to get his treatment in the first place, it necessarily means that his foster mother knew about his HIV-positive status.

Thirdly, Nicky's foster mother and the significant other attachments in her life, including her best friend, who know about Nicky's HIV status continuously check-up as to whether she is taking care of herself (Nicky, 1, p. 25; 33-35). This is done with the best intentions by people who really care about her, but it places Nicky in a difficult position where she is expected to be responsible and yet is treated like a child. This seems to make Nicky tired, sad and angry. This is consistent with Kang *et al's* (2008) finding that HIV complicates the move from dependence to independence for HIV-positive adolescents due to the need for caregivers to ensure drug adherence. The extent of this betrayal though is highlighted by Nicky's love for children, which comes through repeatedly in her interviews:

Ya, children, they they they are not adults. [...] (*Lindsay laughs and Nicky joins her*) If you said "no", they will sit. Ya, that is what I love about them. [...] And if you said "that's, that's right, and that's wrong" they will listen. But adult, if you said "no", they will ask why (Nicky, 1, p. 22-23)

Nicky loves children because they are not adults. It is possible that for Nicky adults do not listen and constantly question her. Children, alternatively, listen to Nicky, do not tell her what to do, and let her be in control.

Lastly, in contrast to Sihle and Nicky who made no mention of it, Siphon is challenged by not having a positive male attachment figure. This was demonstrated in his drawing a car, with such care, for Interview 1 (see Appendix M; Siphon, 1, p. 25). It later transpired that the car represented his uncle (Siphon, 1, p. 25). It is thus a transitional object (Ivey, 1990). However, while Siphon is attached to his uncle, his uncle is not constant and so seems to be experienced as abandoning. Siphon has two other male attachment figures: his father, whom he never knew

and who abandoned him; and his older brother, who while constant does not appear to be perceived as good. Thus, Siphho has no positive male role model in his life. As such, his concerns with masculinity, and what it is to be a man, come through repeatedly in his interviews (Siphho, 1, p. 6; 25).

Nicky and Siphho's current attachment figures' shortcomings of sometimes not understanding the participants, not disclosing the participants' HIV statuses immediately, constantly checking that the participants are taking care of themselves, and not having a positive male attachment confirms the phantasy that others cannot be trusted. As discussed later (see 5.2.2) this has significant ramifications for the experience of intimacy.

Sihle is again in contrast to Nicky and Siphho because of the constancy of her attachment figure. In addition, Sihle's mother is the only attachment figure who disclosed Sihle's HIV-positive status the first time that Sihle asked:

*(Sihle speaking in a strong, possibly angry, voice and using the rolled paper to emphasise what she's saying by either using it to point to herself or to the floor) My mom told me then when I was six that I was HIV positive. Because I was asking why I'm the only one who always keeps taking medication [...] (Sihle points to herself with the roll, swings her legs, and ends speaking much more softly) And my mom said because I'm HIV positive (Sihle, 1, p. 27)*

Sihle begins the narrative in a "strong, possibly angry, voice". This could be the unconscious expression of her cut-off anger towards her mother. As a six year old Sihle noticed that she was the only one who took medication every day and when she asked about it Sihle was provided with the true explanation. This has two implications: firstly, it means that Sihle learnt about her status much earlier than Nicky and Siphho and so did not have to process it for the first time as an adolescent; and secondly, it means that Sihle's mother did not betray Sihle's trust.

Sihle's mother was authentic and truthful in her response to Sihle. This allowed for Sihle to internalise a sense of her mother as trustworthy (Ivey, 1990). This is even more so given that her mother has not passed away and abandoned her. In addition, Sihle's mother's authenticity allows for the transitional space (Aitken, 2001; Ivey, 1990) where Sihle and her mother meet to be authentic. Finally, Sihle's mother's disclosure makes explicit the unconscious third person in their relationship, or at least in Sihle's mother's mind: HIV (Long, 2009).

Therefore, Sihle's mother's disclosure about Sihle's HIV status enabled Sihle to experience

an authentic, trusting relationship, which has had positive ramifications for her experience of intimacy. The danger is, though, that HIV will come to completely dominate their relationship.

Thus, while Nicky and Siphó's current attachment figures appear to be an improvement on the participants' first attachment figures, the attachment figures have still been unable to provide Nicky and Siphó a relationship where the other is trusted completely. Sihle's mother in contrast has been able to do this. However, as discussed previously, Sihle's mother has failed to understand Sihle at times. In addition, the focus on HIV within Sihle and her mother's relationship has meant that Sihle conceives of herself as dangerous. Thus, all three participants have experienced elements of both good and bad attachment, which will then necessarily inform their experience of intimacy.

### 5.2.2 The badness (and untrustworthiness of others, the world and the self)

Coming out of the participants' significant attachments just discussed, it can be seen that all three have had elements of good and bad attachments; however the bad attachments appear to be a more common narrative. This will necessarily impact on how participants view themselves, others and the world (Segal, 1992), which will then impact on the participants' experience of developing close and intimate relationships.

Nicky and Siphó both articulated that others are perceived as uncaring, mean, judgemental and rejecting:

Maybe they [the adults] all drink and now that child is hungry but can't cook for themselves, and ends up going to sleep at my home (Siphó, 2, p. 18).

...I was thinking that...when maybe...everyone is not supposed to do it [have sex] because there are people, maybe a person has sex...then they fall pregnant. When they give birth to the child they just throw them away at wherever (Siphó, 2, p. 17)

*(On "mmm" Nicky's whole body softens – obviously empathising)* For example, mmm.... There is this child in my community, she is disabled [...] But others, they like, they, they like to laugh [...] Even if she is crying I just... try to comfort her and say – [...] "No. Just ignore them." [...] "They are idiots" (*"Idiots" said angrily/powerfully*). [...] "If you watch, if you listen to the idiot, you won't go anywhere. Idiots are just idiots. They will keep saying things about you – [...] Even if you are right, ya. (Nicky, 1, p. 22-23)

Yoah, in our new, in our generation people they, they judge, they are so judgemental, ya, if you said something to, to this person he will just... spread it, ya (Nicky, 2, p. 67)

The above narratives demonstrate the world and others as Siphon and Nicky perceive it. Siphon describes children starving, not being taken care of, and “throw[n] away”. Nicky describes the community being mean, uncaring, and judgmental. These experiences serve to confirm Nicky and Siphon’s introjects based on their relationships with their significant attachment figures (Ivey, 1990; Segal, 1992). Therefore, these experiences confirm Nicky’s and Siphon’s phantasies that others and the world are untrustworthy, abandoning and uncaring. It could be argued that this is consistent with the message perceived by individuals concerning society’s encompassing stigma towards HIV (Brown *et al*, 2010), as demonstrated by the metaphors associated with the disease (Rohleder & Gibson, 2006).

In addition, both Siphon and Nicky express concern about people gossiping. This makes it difficult to tell others about their HIV status as others cannot be trusted to keep the boundaries of confidentiality. This is especially threatening given HIV-related stigma. For example, Nicky stated:

- N: 2008 ya... there was this, this classmate, her mum is a social worker. She was my social worker. But she, she, she, she disclosed my stat- status  
L: To her daughter?  
N: (*Nicky becomes very sad while she is talking*) To her daughter and her daughter was... talking about it at school and the other children  
L: Sjoie  
N: were just pointing fingers on me  
L: Woah  
N: Ya  
L: And what were they saying about you?  
N: ... They, they discussed it, some of them  
L: That you were HIV positive?  
N: Ya. They said “no, they are lying”. Some of them they said “yes, we know that because we saw.. the spots on her face” and all that, ya  
L: Sjoie... How do you... cope? Or what did you do? Or?  
N: (*Heaviness*) Ai. It wasn’t easy. I was crying, ya (Nicky, 1, p. 38)

Nicky’s stuttering in “she, she, she disclosed my stat- status” unconsciously betrays the anxiety and trauma that this incident held for Nicky. Nicky’s description of the other children pointing fingers at her visually represents her ostracism with all others against her. This is consistent with the literature on HIV-related stigma (Brown *et al*, 2010; Deacon *et al*, 2009; Rohleder & Gibson, 2006) and the idea that stigma reinforces an individual’s sense of isolation (Rohleder & Gibson, 2006). Nicky’s heavy tone in her response to how she coped

and her admission of crying further emphasises how difficult this was for Nicky. For Nicky the trauma of this incident, of others knowing her HIV-status without her consent, was as big as the trauma of finding out her HIV-positive status. Rohleder and Gibson (2006) explain that an HIV-positive diagnosis is traumatic because it brings about concerns about death, infecting others and stigma. However, it seems that it was as dangerous for Nicky to be internally attacked by HIV as it was to be externally exposed to others about it. This demonstrates the powerful negative role of stigma in HIV-affected children's psychosocial wellbeing (Deacon et al., 2009).

Nicky's and Siphó's experiences and perceptions of others and the world confirm the participants phantasies (Segal, 1992) that others and the world are untrustworthy, uncaring, mean, judgemental, abandoning, unaccepting and gossiping. Thus, Nicky and Siphó's primary object relations have become internalised, metabolised and projected out (Ivey, 1990) such that others and the world are perceived as bad and dangerous. Therefore, intimacy is extremely threatening for Siphó and Nicky as it requires the participants to make themselves vulnerable to the uncaring, untrustworthy, meanness of others and the world.

Given Sihle's attachment figure and her related object relations, Sihle does not seem to experience others and the world in as negative terms as Nicky and Siphó. For example:

- T: Do the people in your community, near your house, the people you live next to, do they know that you're HIV positive and how do they feel about it? How do they treat you?
- S: (*Sihle's tone quite quiet and she swings her legs and fiddles with the paper as she talks*) They—they treat me well. I even tell my friends that I have it (Sihle, 1, p. 23)

Sihle reported that others treat her well, even to the point where she discloses her status. However, Sihle later tells a different narrative about how her peers at school will not play with her so that she only has one friend. In addition, Sihle admits to being scared of being rejected for her HIV status. This remains consistent with other research where HIV-positive adolescents describe similar concerns about rejection following disclosure of their status (Fernet et al, 2007; Ferrand et al, 2010; Kang et al, 2008). Therefore, it is possible that Sihle is defensively cutting-off her negative experiences with others (Bateman & Holmes, 1995).

Siphó and Nicky seem to be externalising and projecting their own sense of badness out into the world so that they can retain a sense of themselves as good (Bateman & Holmes, 1995).

In contrast, Sihle seems to have rather internalised the badness of the world (Ivey, 1990; Klein, 1952). This has the benefit of giving her some control over the badness, makes the world a safer place to be, and lets her mother remain a good object. Both defences make use of splitting though (Bateman & Holmes, 1995). Splitting is when individuals psychologically separate things, others, the world or themselves into ‘good’ and ‘bad’ parts in order to make themselves feel safer (Bateman & Holmes, 1995). Splitting often involves an idealisation of one part and a hating of the other part (Bateman & Holmes, 1995). Given the participants’ use of splitting, it could be argued that all three participants are experiencing persecutory anxieties of annihilation (Hinshelwood, 1991; Lemma, 2003; Segal, 1992). These anxieties come about as a result of the perception that the self is under constant threat (Lemma, 2003). This makes intimate relationships challenging because others, in the case of Nicky and Sipho, or the self, in the case of Sihle, are too dangerous for intimacy to occur safely. This is demonstrated in the fact that all three vertically-infected HIV-positive adolescents narrated themselves as isolated and alone.

### 5.2.3 Boundaries

The participants’ perceptions of either themselves or others as bad suggests that all three participants do not feel safe interacting with the world and others. However, this perception is further motivated by the lack of boundaries in the participants’ lives. According to object relations theory the concept of boundaries is central to human development (Ivey, 1990; Winnicott, 1971). Boundaries facilitate the differentiation between what exists inside and outside of ourselves and allow for a sense of safety (Bateman & Holmes, 1995; Segal, 1992). From this perspective a sense of boundariedness is necessary for a person to function in the world. Given the importance of boundaries, this subtheme will discuss firstly how threatening it is for the participants not to have or not to trust boundaries; and secondly, how the participants use boundaries, often splitting, to make intimacy safer.

A lack of boundaries results in a sense of a loss of predictability and control. Control was a central theme for all the participants. When talking about adolescents who are HIV-negative Sihle stated:

*(Sihles shakes her head, smiles/almost laughs and leans forward adjusting her legs; talks gesturing with the roll) I’m happy because, I’m happy but...the thing I’m—that... (Shakes*

*head*) I'm happy that, that they don't have it but I have to tell them how they should control themselves too (Sihle, 1, p. 36)

Sihle's repetition of "I'm happy", together with the pauses and her shaking her head, suggests that she struggled to state why she is happy. It could be argued that this is because there is a conflict for Sihle in negotiating her relationship with HIV-negative adolescents. The phrase "they should control themselves too" is significant. This is because it represents the internalisation of HIV-related stigma (Deacon *et al.*, 2009) as the loss of control is perceived as bad and associated with irresponsibility and HIV-infection. However, the phrase also demonstrates that Sihle feels that she always has to be in control of herself. This means that she cannot relax and *be*. In other words, Sihle struggles to find a transitional, resting space (Winnicott, 1971).

Nicky repeatedly maintained throughout her interviews that others expect more and do not respect boundaries. Nicky stated that her Grandmother was raped and consequently contracted HIV and passed away. When asked how she thought this impacted on her perception of sex Nicky stated:

Ah, it impact a lot because... in other cases there are people who don't understand what "no" means (Nicky, 2, p. 69)

*(Said quite stiltedly)* But most of the boys, when, when it comes to kissing they expect more (Nicky, 1, p. 51-52)

From a young age Nicky had the perception that others do not listen to the word "no" and as such do not respect boundaries. She also expects others to always expect more. Thus, Nicky perceives boundaries to be fluid and easily broken. This is difficult because the external world is internalised into phantasy (Ivey, 1990; St. Clair, 2000). In phantasy the boundaries of object relations theory (Ivey, 1990; Winnicott, 1971) are also fluid and easily broken. This is a terrifying position to be in and one that would result in persecutory anxieties of self-destruction (Lemma, 2003). This has impacted negatively on Nicky's intimate relationships.

The threat of intimacy refers to both emotional and physical intimacy and the related blurring of boundaries. When explaining her drawing from Interview 2 (see Appendix J) Sihle stated:

T: so you wanted to—you didn't want to mix your colours? To keep them separate?  
S: yes  
T: she says yes  
L: ooh... ok so sexuality's colours are separate?

- T: so then sexuality's colours are—are separate? (*Sihle nods*) she says yes  
 L: sho. Uhm... so do the colours ever mix?  
 T: do the colours ever mix? The colours of sexuality?  
 S: no (*shakes head*)  
 L: no? Will they ever mix, like in the future?  
 T: will they ever mix, like in the future?  
 S: (*shakes head*) (Sihle, 2, p. 12)

When asked to draw sexuality Sihle drew big circles in different colours. She stated that she did this because she wanted to keep sexuality's colours separate so that the colours will never mix. This demonstrates that mixing, especially in the context of intimacy and sex, is threatening for Sihle. Sihle appears to find the lack or blurring of boundaries extremely threatening. This is similar to Nicky, and is further indicative of Sihle's use of splitting and persecutory anxieties (Lemma, 2003).

All three participants therefore make use of boundaries to make themselves or others feel safer (Bateman & Holmes, 1995; Segal, 1992). This is usually done through the defensive use of splitting (Bateman & Holmes, 1995). Nicky and Sihle stated:

E-history. Our, our forefathers [...] Ya, they, they used to do sex... with, with people that they love, with the, with the person that you love [...] You don't do sex with strangers [...] Which is also right because on the olden days there were no rape [...] Ya, during that time. And on the olden days there were no diseases like e-sexual (Nicky, 2, p. 29)

- T: (*Sihle starts rolling the paper slightly and slowly*) How does that feel to you? That you have all these parts [HIV, friends, home and church] inside you in your little body?  
 S: (*Sihle looks down and there is quite a pause... she leans forward, nodding her head when she starts speaking, rolling the paper slowly, and has a big smile*)...I choose one part (Sihle, 1, p. 48)

Nicky splits the past and present, idealising the past as a time when rape and sexual diseases did not exist, and by implication hates the present. In contrast, Sihle splits herself into only "one part". Sipho splits sex off as a bad object following his realisation about the possible negative consequences of sex (Sipho, 2, p. 27). This splitting allows Nicky a concept of some people as good, trustworthy, responsible and respectful of boundaries; Sihle to contain her own sense of dangerousness; and Sipho to defend against his own possible sexual desire. Thus, the participants' defensive use of splitting protects the participants from psychic pain and enables daily functioning (Lemma, 2003).

Other than splitting, the participants make use of other, sometimes rather arbitrary, methods to make themselves feel boundaried and safe. For example, Nicky has a rule for herself that she will not have sex with someone until they have been dating for two years (Nicky, 2, p. 37). All three participants advocate the use of condoms in order to make sex possible (see 5.4.3.1). Lastly, Sihle makes use of the church to provide rules and boundaries (Sihle, 1, p. 56). It appears that the church's rules make it easier for Sihle to cut off sexuality and sexual intimacy and it makes death, and therefore HIV with its link with death (Kelly *et al*, 2008; MacGregor, 2009), easier because of its promise of eternal life.

#### 5.2.4 Desire for intimacy

The use of boundaries is necessary because despite how threatening intimacy is for this research's participants, all three expressed a desire for intimate relationships. The participants narrated a desire for togetherness, having trusting relationships, and being understood and accepted. Nicky and Siphon stated:

I hope that one day I will find Mr Right [...] (*Nicky starts crying somewhere during the beginning of this – very heavy/sad*) Someone who will understand me, someone... who will listen to me if I said no, and someone who, who will be there for me, someone who won't judge me, someone... someone (*Nicky clears her throat and Lindsay touches her arm*), someone who... who, who won't judge me of, who won't judge me because I'm, I'm positive (*Nicky seems angry*) and someone who won't talk about me on all that stuff, and someone who... who understands my opinion, if I said something he will understand that "no he mean, she meant ya", all that stuff. (Nicky, 2, p. 66)

T: she says she's wondering if you're gonna tell your wife that you're HIV positive  
 S: yes  
 L: yeah? Yeah. Why is she ok to tell?  
 T: why are you able to tell her?  
 S: cause...  
 T: or, why is it ok to tell her?  
 S: (*silence*) because I will trust her because she's my wife (Siphon, 2, p. 24ish)

Nicky's use of the name "Mr Right" immediately denotes that this is an idealisation (Segal, 1992). This is difficult because no actual person will be able to live up to this idealisation (Segal, 1992). Siphon describes a similar phantasy of finding the perfect partner with whom he can experience togetherness in a trusting relationship. Nicky's phantasy is that this other will understand her, listen to her, be there for her, accept both her and her HIV status, not check-up on her that she is taking care of herself and respect her boundaries. Nicky later said that the tone of this narrative was so emotionally loaded because she is scared that she will never

find an other like this. This fits with her beliefs about others (see 5.2.2). Nicky and Siphó's idealisation of their future partners is possibly a defence against their perception of others as bad.

The participants' desire for intimacy can be understood within the context of object relations theory because it argues that human beings' most fundamental need is for a connection and relatedness with others (Epstein, 1991, p. 835). Therefore, irrespective of how threatening intimacy is for the participants, the participants will always have a need for intimacy. Li *et al* (2010) found that her vertically-infected participants also expressed a desire to connect with others. Literature further states that people who are HIV-positive have better outcomes if they experience themselves as being supported by others (Kelly *et al*, 2008). Thus, despite the threat of stigma, there is still a desire for connection.

Given the negative connotations associated with intimacy, the desire for intimacy is necessarily conflicted. In order to cope with this, the three participants often cut off the most threatening parts of intimacy as a defence (Lemma, 2003). This will be discussed in further detail later (see 5.3.2 & 5.4.4.1).

The vertically-infected HIV-positive adolescents in this research experience intimacy as extremely threatening. It appears that the participants have experienced themselves as not understood in both their early and current attachments. Nicky and Siphó experience the world and others as scary, abandoning, untrustworthy and disrespectful of boundaries such that it is not safe for the participants to open themselves up to others. Sihle, however, experiences herself as dangerous, and therefore intimacy as not safe for the other. In other words, for this research's participants intimacy endangers either the self or the other. This will necessarily impact on the participants' experiences and perceptions of sexual intimacy (see 5.4). However, despite this, the participants still demonstrated a strong desire for and idealisation of intimacy.

### 5.3 The experience of the self in relation to HIV: "Her life is depending on pills"

The self is defined as the psychodynamic self. This is a self that arises out of relationship with others (Ivey, 1990; Thomas, 1996) with the aim of differentiating between the self and

the not-self (Abraham, 2007). This self is conceived of as “a series of selves” that can be referred to in parts (Thomas, 1996, p. 315).

Having argued that this research’s vertically-infected HIV-positive adolescents experience intimacy as extremely threatening given their early and current object relations, the current theme discusses the participants’ experience of self in relation to their HIV-status. According to Abraham (2007), Ivey (1990) and Thomas (1996) the self develops out of an individual’s intimate relationships with others. As such, the participants’ experience of intimacy constructed a particular sense of self for each participant which, together with the meaning that the participants attach to HIV, impacts on the participants’ experience and perception of sex and sexuality. Therefore, the participants’ sense of self needs to be understood before their experience of sex and sexuality can be discussed.

### 5.3.1 Self = HIV = death

Literature consistently states that identifying oneself as someone who is HIV-positive is extremely challenging (Hayes, 2012; Kelly et al., 2008; Rohleder & Gibson, 2006). This is in part because of the multiple meanings attached to HIV and being HIV-positive (Bardhan, 2002; Kelly et al., 2008; Rohleder & Gibson, 2006). For example, HIV is linked with death (Hayes, 2012; Kelly et al, 2008; Sontag, 1991, in Rohleder & Gibson, 2006), sex and promiscuity (Hayes, 2012), irresponsibility and badness (Deacon et al, 2009; Sontag, 1991, in Rohleder & Gibson, 2006), suffering (Kelly et al, 2008), and discrimination due to stigma (Deacon et al, 2009; Kelly et al, 2008) to name a few. These negative meanings attached to HIV necessarily impact on the experience of a self that is HIV-positive.

For all three participants HIV was dominant in their sense of self. Siphon, Nicky and Sihle stated:

- T: she says since you guys spoke about the drawing right, is there anything else you think she needs to know about you? That’s important
- S: yes
- T: yes?
- S: (*Siphon adjusts his chair, wipes his face, and put his earphones in his mouth*) ...uhm. I’m HIV, I got it from my mom [...] (*Siphon moving around constantly and fiddling with his earphones*) also I take ARVs. It never comes to me; maybe I have something, where I think about it. It’s just something that’s in me (Siphon, 1, p. 29)

- N: I'm just being angry with myself [...] I just wish that I wasn't born  
 L: At all?  
 N: Ya  
 L: ... Why?  
 N: Because if I wasn't born, I shouldn't have been positive (*Nicky becoming emotional*)  
 [...] (*Lindsay sighs and the tone is very heavy while she waits for Nicky to speak*)  
 Because now my life is so difficult (*Nicky starts crying*) (Nicky, 2, p. 70 – 72)

(*Softly*) Sometimes... I think I decide to happy with my health, to make my face big (Sihle, 1, p. 62)

Sipho describes his HIV-positive status and medication as something that is important to be known about him. This suggests that Sipho considers his HIV-status to be a dominant part of his sense of self. His constant movement unconsciously denotes anxiety around disclosing this though. The phrase “I'm HIV” proposes that Sipho has identified himself with HIV in such a way that he cannot be separated from it. Nicky wishes that she had not been born so that she “shouldn't have been positive”. This suggests that for Nicky the only way that she can perceive of herself as not positive is for her to not to have been born. Thus, as with Sipho, it seems that Nicky perceives herself and her HIV to be inseparable. Sihle's drawing that she did for Interview 1, which originally only comprised of things related to HIV and being sick (see Appendix I), suggests that Sihle's sense of self is almost exclusively her HIV-positive status. Sihle's quote supports this idea. Sihle is only able to be happy and have a “big face” if she chooses to be happy with her health. This is significant because in psychodynamic projective drawings the head is viewed as representative of the individual's sense of self (DiLeo, 1983). To this effect, Sihle has “joined” HIV and made her whole life about HIV to the extent that during the interview it seemed that it was the first time that Sihle had ever considered herself to be separate from or something other than HIV-positive (Sihle, 1, p. 66).

It seems that for all three participants their sense of self is intimately connected with their HIV status. It would appear that the participants have internalised and identified with their HIV-statuses (Ivey, 1990). This represents a lack of differentiation between internal and external reality such that the self has been identified with the participants' external reality (Abraham, 2007; Thomas, 1996) of being HIV-positive. In this sense the participants are as much themselves as they are HIV-positive. Rohleder and Gibson (2006) describe a similar internalisation and identification of HIV into the self.

This identification with HIV is challenging because of the negative meanings attached to HIV. The analysis found that, consistent with other research (Hayes, 2012; Kelly *et al*, 2008; Sontag, 1991, in Rohleder & Gibson, 2006), all three participants identified HIV as imminent death. Therefore, by internalising and identifying HIV with the self, the participants also associate death and destruction with the self. This suggests that the participants are living with a constant fear of annihilation, destruction and engulfment (Hinshelwood, 1991; Lemma, 2003). The self is constantly under threat and, as such, it is likely that primitive, persecutory anxieties dominate the participants' experience (Lemma, 2003). From a psychodynamic perspective, this is challenging because this is not a secure, safe place from which to develop a self (Ivey, 1990). Sihle and Nicky stated:

*(Sihle opens up her drawing so it is completely showing again; speaks in a soft, thick voice)*  
I'm scared of... I'm scared of dying *(Sihle starts crying again)* (Sihle, 1, p. 19)

L: How often do you feel like killing yourself?

N: *(first two pauses very long and she looks on the brink of tears)* Yoah... ah, it's been a while because... ever since my grandmother passed away and I watched her...

L: Suffer

N: *(Nicky starts crying)* Suffer, then I wasn't ok... and when my friend was sick and I went to hospital to say... she was on nappies [...] And I saw her and I said one day, it will be me [...] *(Lots of emotion)* And one day... it might be me who stand there... waiting for others to change me nappies, waiting for people to change me nappies... or waiting for needles, for injections... whose, whose, whose, who, who, who is her life is depending on pills and people said things that you will be ok, even though I won't be ok (Nicky, 1, p. 76 – 77)

Sihle's crying demonstrates that for Sihle her sense of her own death is both imminent and very real. Nicky takes this even further by being suicidal. This came about as a result of witnessing her Grandmother's and her friend's HIV-related deaths. This is consistent with research that links witnessing someone close pass away due to HIV and decreased mental health (Kelly *et al.*, 2008). MacGregor (2009) similarly describes the trauma of "witnessing others dying ugly, emaciated deaths" (p. 93). It would seem that witnessing an other's death due to HIV reminds someone who is HIV-positive of the terror of their own potential bodily disintegration and loss of control (MacGregor, 2009; Smiley, 2004). "I saw her and I said one day it will be me" demonstrates that Nicky completely self-identified with these deaths. This idea is supported by Nicky's crying. "Her life is depending on pills" is significant because Nicky's life is already dependent on pills, and so her stuttering prior to this phrase suggests that Nicky is both consciously and unconsciously aware that she is already dying. In this sense her suicidality is actually a way of moving into the future, contrary to what her foster

mother told her (see quote in 5.2.1). Nicky's narrative of being so close to death is reinforced by those around her who stated that they did not expect her to survive (Nicky, 1, p. 60). Therefore, it is not surprising that Nicky cannot experience or conceive of herself as "ok".

Thus, for these vertically-infected HIV-positive adolescents their sense of self is their HIV. However, the participants have equated HIV with death, and as such, their sense of selves as well. This means that the participants' sense of self is constantly under threat, and as such the participants probably experience paranoid anxieties. From Klein's perspective, this is going to have a devastating impact on these participants' experience of self.

#### 5.3.1.1 Self and body as sick

The participants' identification with HIV seems to be contributed to, and reinforced by, the fact that the participants have either been sick or at the very minimum take medication every day. This is because medication signifies sickness. Nicky stated:

*(From "I can't take it any longer..." said very quietly and mumbled) So ya, I said "I can't take it any longer". Cause the treatment, yoah... medication (Nicky shakes her head)... it's not my thing. I said, "I started eating medication, taking medication when I was... three years cause my grandmother told me that I was on medication". And I said "till now? Still on medication?" I said "no, that's not healthy". (Nicky, 1, p. 72)*

Nicky's quieter tone when saying, "I can't take it any longer" suggests a desperation and hopelessness. Nicky's use of the word "yoah" and the following silences and shaking of her head further support the content of this quote that she does not like taking medication. This is because she has continued to take it since she was three years old. Her question, "till now?" seems to have an irate, aggressive tone to it, suggesting that Nicky is angry about the fact that she has to take medication. This idea is supported elsewhere in Nicky's interview. The phrase "that's not healthy" suggests that there is something harmful about taking medication for so long.

Nicky's concern with the safety of the medication has been identified in research (MacGrgor, 2009). In addition, the former president, Mbeki, and former health minister, Msimang, themselves raised similar concerns (Richey, 2008). In this way, Nicky's concern is possibly an example of how the "political overtakes and orientates the personal experience" (MacGregor, 2009, p. 92). Nicky's treatment seems to be more traumatic for her than her sick

body. By taking medication she is acting like a person who is sick, which is confirmatory of her self-concept as sick. In addition, the medication possibly serves as a constant reminder of her HIV status. It is possible that this is the case for Siphon and Sihle too.

Thus, the experience of individual health and medication is constructed and immersed in symbolism and meaning (Bardhan, 2002; Bendelow, 2009). This is supported by Kelly *et al*'s (2008) finding that psychosocial factors significantly impact on ARV adherence.

Siphon denies ever being sick. However, this may be due to the fact that hegemonic masculinity does not allow him to be perceived as weak or vulnerable (Lindegger & Quayle, 2009). This is because hegemonic masculinity demands "physical and emotional toughness" (Segal, 2006, in Lindegger & Quayle, 2009, p. 42). Nicky (1, p. 26) and Sihle however both describe themselves as being very sick as children, and as such have had self-concepts of themselves as sick since they were young. Nicky describes her body and immune system as "weak" (Nicky, 1, p. 75). Sihle describes a traumatic experience more recently:

- T: Please tell us about your intestines  
S: *(Sihle touches her tummy; Sihle points to her left breast; "uhm" is long; Sihle starts talking very strongly but the tone shifts significantly and she ends speaking more quietly or sadly)* My intestines... and my breasts... Uhm my breasts, I was young and my mom asked me why I had a lump on my breast. I told her I don't know, and we went to the hospital. When we got there the doctor said it wasn't cancer but it's a lump that's dangerous. (Sihle, 1. p. 15)

Sihle was asked to discuss her intestines but she instead discussed her breasts. The pauses after "my intestines" and "my breasts" unconsciously suggest that these parts of her body are anxiety provoking for Sihle. She discloses that her breast has a lump that is not cancerous but is still dangerous. Following this extract Sihle stated that the Doctor told Sihle that he could not remove the lump as she might die if he did. Thus, both the HIV-positive individual and medical practitioner lose control and power over the HIV-positive body (MacGregor, 2009; Smiley, 2004). This experience possibly reinforced Sihle's self-concept that death is imminent.

For Sihle and Nicky their bodies are weak and fragile. This is consistent with other literature (Kelly *et al*, 2008; MacGregor, 2009; Smiley, 2004). Nicky stated:

- L: Ok... What makes you angry with yourself?

N: *(Nicky is crying while she is talking)* Ah... ah, it's because every time if I look myself in the mirror, I just saw, I just saw, I just have a picture that I'm struggling, I'm sick, I'm suffering, and people's said, said things about me that I would be fine even though I won't be fine (Nicky, 2, p. 70-72)

Nicky states that when she looks in the mirror she sees an image of herself as “struggling”, “sick” and “suffering”. She sees someone who “won't be fine”. Her crying and use of emphasis during this narrative highlights how emotional and difficult her self-concept is for her. Thus, for the participants, the lived experience of being someone who is sick impacts negatively on the sense of self (Bardhan, 2002; MacGregor, 2009; Smiley, 2004). This is because health and disease are value laden (Bardhan, 2002; Bendelow, 2009) and internalised from external reality into internal reality (St. Clair, 2000). Nicky further stated:

L: And do you like your body? Like how do you feel towards your body?  
N: *(Very sad as she is speaking)* Sometimes I just felt like hurting myself. Ya. Sometimes I just feel like... just wanna kill myself. (Nicky, 1, p. 27)

Nicky dislikes her body to such an extent that she sometimes wants to hurt and kill herself. From an object relations perspective, objects cannot be trusted unless they are reliable and constant (Ivey, 1990; Lemma, 2003), which the participants' bodies are not. Nicky cannot trust her body not to get sick or hurt. This is significant because external vulnerability is introjected (Ivey, 1990; St. Clair, 2000) such that the self also becomes vulnerable and easily hurt. Therefore, once again the participants are experiencing persecutory anxieties of annihilation and destruction (Lemma, 2003).

#### 5.3.1.2 Self as bad, dangerous and unlovable

Given the participants' identification with HIV, death and sickness, a pertinent narrative for the participants was of the self as bad and dangerous. The participants' sense of self was difficult to negotiate. For example Siphos stated:

T: How do you feel about people saying a person makes themselves get HIV when you didn't make yourself?  
S: *(Silent for about 32 seconds – Siphos spends the time fiddling with his earphones but otherwise seems reasonably calm)*  
L: it's a difficult question?  
S: yeah (Siphos, 1, p. 39)

Siphos' use of silence marks the use of avoidance as a defence (Lemma, 2003). He is possibly trying to avoid engaging with society's perceptions about HIV in relation to his own

status. This suggests that it is difficult for Sipho to negotiate HIV-related stigma with his self-concept. Stigma thus impacts negatively on the participants' sense of self (Rohleder & Gibson, 2006). This can be seen with Nicky and Sihle whose sense of self as bad and dangerous seems to stem mainly from their HIV-positive status:

*(Sihle almost hits her rolled up drawing into her one hand to punctuate what she is saying) I think that maybe I could have one [boyfriend] or that I tell him that I'm HIV positive so then he should be careful, he should save himself (Sihle, 1, p. 37)*

Sihle states that either she could have a boyfriend or she could disclose her status so that he can "save himself". There are two implications from this: firstly, Sihle perceives herself as someone that others need to be "saved" from. Thus, as discussed previously (see 5.2.1.1), Sihle perceives herself as dangerous. Nicky also perceives herself as dangerous (Nicky, 1, p. 76). This is in line with other research where participants similarly described themselves as 'dangerous' (Green, 1994; Kelly *et al*, 2008; Rohleder & Gibson, 2006). Secondly, Sihle seems to believe that if she discloses her status the other's decision will be to not to be in a relationship with her. She confirms this in Interview 2 (Sihle, 2, p. 27-38). Deacon *et al* (2009) and Green (1994) describe similar concerns with rejection following disclosure. Fernet *et al* (2007) and Kang *et al* (2008) describe this specifically in relation to HIV-positive adolescents. Nicky stated:

*And I'm different them because I'm positive and their immune system is clean and mine... is not (Nicky shakes her head and looks down) (Nicky, 1, p. 75)*

Nicky states that she is different to others because of her HIV status. She states that others' immune systems are "clean". "Clean" implies something good, desirable and pure. However, Nicky's immune system "is not". This suggests that for Nicky her immune system is dirty, bad and undesirable. As such, it is inferior to others' immune systems. This sense of self as dirty was also identified by Rohleder and Gibson (2006).

This perception of the self as dangerous and dirty is in line with Rohleder and Gibson's (2006) concept of people internalising HIV-related stigma into their self-concept to such an extent that a "spoiled identity" is acquired (p. 40). This is because stigma attaches negative meanings to HIV (Bardhan, 2002; Deacon *et al*, 2009; Kelly *et al.*, 2008; Rohleder & Gibson, 2006), which then become internalised into the self (Ivey, 1990; St. Clair, 2000). In this way, the participants experience symbolic, felt and perceived stigma (Deacon *et al*, 2009). The

suggestion that Nicky and Sihle have internalised a spoiled identity is supported by Nicky's inability to hear compliments about herself (Nicky, 1, p. 15; 19; 42) and Sihle's expectation of rejection if she discloses.

While Siphon also conceives of himself as bad, in contrast to Nicky and Sihle this seems to be mainly due to his early relationships:

- T: She's asking if you could tell her about how you ended up living with your aunt?  
Like what happened before you went to live with her?
- S: *[long silence]* we were in Port Elizabeth. I lived with my mom and dad. Then when—  
my mom died...because my...dad didn't care he asked my aunt to take us and put us  
next to her [as in have them live with her] [...]
- T: how does that make you feel?
- S: makes me feel sad (Siphon, 2, p. 19)

Siphon's silence prior to answering unconsciously suggests how difficult his parents' abandonment was for him, as does the pause prior to stating that his "dad didn't care". This echoes his description of parents "throwing away" their children. This conversation was the first time that Siphon answered a question about how he felt. This suggests that Siphon's sense of sadness is so dominant that he cannot defend against it.

In phantasy, Siphon's mother's death and his father's not caring are internalised to say something about Siphon (Ivey, 1990; St. Clair, 2000). This is possibly that Siphon cannot be cared about. From a Kleinian perspective, this abandonment confirmed Siphon's already horrifying internal parental phantasies (Hinshelwood, 1991). Both Siphon's and Nicky's permanent abandonment by their parents means that the oscillation between loving and hating their parents (Hinshelwood, 1991) has been cut short so that it is unlikely that the participants have been able to create internal objects of themselves and others that are both loved and hated (Hinshelwood, 1991), good and bad. This suggests that Siphon and Nicky struggle to whole object relate (Hinshelwood, 1991), a characteristic which also seems to be present in Sihle.

The difficulty to internalise a sense of whole object relating proposes that the participants are going to use splitting in how they think of themselves and others (Bateman & Holmes, 1995). However, splitting cannot be used without splitting the self too (Segal, 1992), which suggests that the participants experience themselves as part objects rather than whole objects (Ivey,

1990). This fits with research in the area (Long, 2009) and the argument that the participants experience persecutory anxieties (Bateman & Holmes, 1995).

In addition, Sihle's concern about being rejected following disclosure, and Nicky and Siphos refusal to disclose, suggest that the participants cannot conceive of their whole selves, their HIV included, being loved or at the very least accepted (Hinshelwood, 1991). The same can be said for the significant number of participants in other research who similarly report concerns of rejection (Deacon *et al*, 2009; Fernet *et al*, 2007; Green, 1994; Kang *et al*, 2008). Thus, it is possible that this research's participants experience themselves as unlovable. It is even more so the case given that, in addition to internalising HIV-related stigma, the participants' identification with death means that the participants are developing a sense of self based on absence and constant threat. This makes it very difficult for all three participants to internalise a sense of themselves as good (Ivey, 1990; Thomas, 1996). Therefore, it is argued that at times all three participants experience themselves as bad and unlovable.

### 5.3.2 Impoverished and cut-off selves

In addition to the probability that the participants experience themselves as part objects, it is also argued that the participants have an impoverished sense of self. This impoverished self can be seen from the drawings that each participant did in Interview 1 (see Appendix I; K & M). Sihle drew only her sick body, Nicky drew a stick figure with a box around it, and Siphos drew an empty outline of a body. Nicky's and Siphos drawings did not even have faces. Given the participants' ages, this is extremely basic and impoverished (DiLeo, 1983).

Such an impoverished sense of self is consistent with the participants' identification with death and absence (see 5.3.1) and with their sense of self as vulnerable and unreliable (see 5.3.1.1). Maughan-Brown (2007, in Deacon *et al*, 2009) describes HIV-positive populations as experiencing a "lack of self-efficacy or confidence" (p. 110). Hackle *et al* (1997, in Rohleder & Gibson, 2006) describe HIV-positive populations as experiencing "helplessness and loneliness" (p. 27). Ferrand *et al* (2010) and Li *et al* (2010) both describe HIV-positive adolescents as experiencing multiple challenges such that adolescents express needs for the most basic of requirements. Thus, while literature does not explicitly refer to 'an impoverished self' in relation to an HIV-positive diagnosis, it does describe HIV-positive

people as experiencing states that are consistent with the concept of an impoverished self. This impoverished sense of self can be understood from an object relations perspective as the participants' difficulty to internalise significant relationships, specifically the reflections from others about who the participants are, into the internal reality of the self (Ivey, 1990; St. Clair, 2000).

In addition to the impoverished drawings, Siphó and Nicky both expressed a detachment from their human figure drawing. The impoverished nature of, and his detachment from, the drawing Siphó did of himself stands in stark contrast to the care and time that Siphó took with drawing the car. Nicky stated that she felt nothing in Interview 1 while drawing or writing. From an object relations perspective the self can only be known through others (Thomas, 1996). Therefore, given that the participants do not experience themselves being known or understood by others (see 5.2.1), the participants cannot know or be attached to themselves either. When Nicky was asked how she would like her drawing to look she stated:

*(Nicky giggles)* Ok. Um, it's like a flower cause there no eyes, nothing [...] Ya... or a cartoon  
(Nicky, 1, p. 8)

Nicky describes wanting her drawing of herself to look like a "flower" or "cartoon". This suggests she wants the drawing of herself to be based on fantasy. In addition, Nicky wants the drawing to have "no eyes, nothing". This possibly reflects a desire for the drawing either to reflect nothing about her or to reflect her own sense of internal emptiness. Thus, it seems that Nicky does not want to see or know herself as she is. This is consistent with her suicidal ideation and how she describes feeling when standing in front of a mirror (see 5.3.1 & 5.3.1.1). It is also consistent with her possible internalisation of a spoiled identity (Rohleder & Gibson, 2006; see 5.3.1.2).

The idea that the participants are experiencing persecutory anxieties, and so are unable to see themselves as acceptable whole objects (Segal, 1992), means that the participants are always going to be presenting only a part of themselves to others. This is exactly what the analysis revealed. All three participants ignored or cut off parts of themselves, whether it was their bodies, sexuality, HIV or everything except their HIV.

Nicky and Siphó cut off or hide the HIV part of themselves, especially from others. Nicky stated that her friends judge people who are HIV-positive and would not believe that she was

vertically-infected (1, p. 64). She therefore hides herself, and her status, from others. Siphon reported that he likes being an adolescent because it means that he does not think about his HIV status (1, p. 45ish). He has not disclosed his status to anyone and up until the very end of Interview 2 he never thought that he would. The day Siphon found out that he was HIV-positive he went to play with his friends but stated:

- S: I felt like they knew what I had  
T: your friends? Your friends?  
S: yes (Siphon, 1, p. 34-35)

Siphon states that he felt like his friends knew that he was HIV-positive, which reflects quite a suspicious and distrustful approach to his HIV status and as such is reflective of his persecutory anxieties (Lemma, 2003). This anxiety is consistent with the participants' expectation of rejection and abandonment following disclosure of their HIV-positive status (see 5.2.2 & 5.3.1.1), which in turn is consistent with understandings of HIV-related stigma (Deacon *et al*, 2009; Rohleder & Gibson, 2006).

Nicky and Siphon's cutting off of their HIV-status mirrors society's attempt at splitting off HIV through the use of stigma (Deacon *et al*, 2009). This suggests that Nicky and Siphon have internalised HIV-related stigma to such an extent that the participants are actively expressing stigma against themselves (Deacon *et al*, 2009). In other words, the participants are self-stigmatising and self-othering (Sontag, 1991, Rohleder & Gibson, 2006). In this sense, external perceptions have been internalised (Ivey, 1990) and are now acting on a split-off part of the participants' selves: HIV (Segal, 1992).

Significant was how anxious Siphon was, constantly shifting and moving around, prior to disclosing his HIV-positive status in Interview 1 and how he relaxed afterwards. This reveals Siphon's relief at being able to show his whole self to others (Thomas, 1996). It is a relief because, from an object relations perspective, by disclosing his status he had nothing left to hide and so was able to relax and *be* in the transitional space (Ivey, 1990; Winnicott, 1971) between himself, the interviewer and the translator. Thus, Siphon and Nicky's refusal to disclose their HIV-status removes the chance for the participants to rest in a transitional space with others, which could be a contributing factor as to why literature consistently reports HIV-positive adolescents struggling with peer relationships (Ferrand *et al*, 2010; Kang *et al*, 2008; Li *et al*, 2010).

In contrast to Nicky and Sipho, Sihle protects the self by cutting off everything about herself except her HIV status (Bateman & Holmes, 1995; Lemma, 2003). The following extract was an attempt to find something in her drawing from Interview 1 (see Appendix I) other than her sick, HIV body:

- T: She says you see like on the face right? Your eyes and your nose and your mouth are very big. Like maybe they're even bigger than the sick part of you...what do you think about that?
- S: (*Sihle looks again at her picture and is silent, then looks at her hand and mumbles something very softly, starts rubbing her hands together, and shakes her head and shrugs her shoulders and hands*) ...I think... (*Shakes head*)
- T: You don't agree?
- S: (*Sihle speaks slowly*) I think...um that. I think that I'm happy with my health (Sihle, 1, p. 62)

Sihle initially struggles to answer the question. This unconsciously suggests that she experiences anxiety around having different parts of herself, particularly a part that is “bigger” than her HIV. She eventually states, “I'm happy with my health”. The sense is that by acknowledging that she has another, bigger part of herself, Sihle is somehow betraying HIV. This perception seems to be a defence born out of the fear that if Sihle is not exclusively focused on “joining” HIV that she will then pass away. This has resulted in Sihle becoming quite obsessive about or fixated on her HIV status and thus hiding the rest of herself from the world and herself. This researcher could find no literature describing a similar experience of HIV.

The participants' experience of self is thus one that has been impacted on by both their experience of intimacy and the meaning of death that the participants have attached to HIV. It suggests that the participants are developing a sense of self based on absence and threat of annihilation in addition to the external reality of a sick body. It is possible that this made it very difficult for the participants to introject good internal objects and as such the participants experience themselves as bad, dangerous and unlovable. This is reflected in the participants' impoverished and cut-off parts of self.

#### 5.4 The experience and perception of sex and sexuality: “I don't like wrong things like sex”

Having discussed the vertically-infected HIV-positive adolescents' experiences of intimacy and self, their experience and perception of sex and sexuality will now be discussed. This is

because the participants' experiences of intimacy and self impact on how the participants think about sex and sexuality. As such, a significant amount of this theme is supported by the previous arguments of this research rather than academic literature *per se*.

Typically sex is of particular interest to HIV and AIDS because of it being a primary mode of transmission (Halperin & Epstein, 2007). However, this research is focused on the lived experience rather than on sexual behaviour patterns. As such it is interested in the meanings that the vertically-infected HIV-positive adolescents attach to sex and sexuality, their sexual identities (Auslander et al., 2006; Epstein, 1991) and their experiences and perceptions of sex.

#### 5.4.1 Sex as bad

Sex is a highly moralised and emotive subject (Burman, 2008; Hayes, 2012) and even more so with sex's link to HIV and HIV-related stigma (Deacon *et al*, 2009). This has resulted in discourses of sex as bad, dirty and something that people should be ashamed of and blamed for (Deacon *et al*, 2009; Hayes, 2012).

The participants in this research all described sex as bad. None of the participants liked the idea of sex. Sihle made this clear from the beginning of her first interview:

- T: Part of who you are is the fact that you're a teenager, you're in your teens and all of that, and you are also HIV positive and the fact that you were born HIV positive, and also the fact that as you grow you develop feelings, like in terms of sex and things like that. So we want to know that side of you. How you cope with that (*Sihle nods slightly a few times*)
- S: (*Sihle leans back slightly then forward again, all the time shaking her head*) I don't like wrong things like sex (Sihle, 1, p. 4)

The translator stated that part of Sihle's sense of self is her adolescence, her HIV-positive status, and her developing sexuality. Of all these different parts, Sihle focused on only one: sex. Sihle leant back in her chair, almost physically moving away from sex, and shook her head as she stated that she does not like "wrong things like sex". Thus, Sihle's body language supports the content of what she is saying. Sihle's response to the translator suggests that she is overly defensive or concerned with sex (Lemma, 2003). According to Malan (1979), this suggests that sex presents a great deal of anxiety for Sihle.

Sipho similarly described sex as “not nice” because there can be bad consequences following sex (2, p. 9ish). Nicky (2, p. 23) argued that prior to sex people do not consider these bad consequences. Sihle additionally stated that sex makes people cheeky and disrespectful (Sihle, 2, p. 18; 20). Thus, for Sipho, Nicky and Sihle sex is bad. The participants stated:

Sex is a dangerous thing to use (Sipho, 2, p. 13)

Sex, it can be dangerous [...] Because, there are people who don't use it.. responsible [...] Who don't, who don't use protection, who just do it. Just for fun or... just being careless (Nicky, 2, p. 21 – 22)

T: so sex is scary right? There's nothing else about sex?  
S: (*shakes head*)  
T: There's nothing else you can say about it?  
S: no (*shakes head*) (Sihle, 2, p. 14)

Sipho states that sex is dangerous. This suggests that sex can do harm. Nicky agrees with this but qualifies it by stating that sex is dangerous if it is done irresponsibly or in a “careless” manner. Her pauses and repetition of the phrase “who don't” unconsciously communicate Nicky's anxiety around this. Sex is so bad that for Nicky sex cannot be made beautiful (Nicky, 1, p. 10) or be part of a good relationship (Nicky, 2, p. 27). Sihle states that sex is only “scary”. Sihle's hesitancy to answer verbally is possibly indicative of her desire not to engage with the badness of sex.

One of the foremost reasons that the research participants disliked sex, and thought of it as bad, was because of its link with illness and HIV-infection (Nicky, 2, p. 24; Sihle, 1, p.4). Similar concern has been reported extensively in literature (Green, 1994; Kelly *et al*, 2008; Rohleder & Gibson, 2006).

Nicky argues that people should not have sex unless they have been tested and know that they are not sick (Nicky, 2, p. 22). This is consistent with Hayes' (2012) argument that discourses surrounding sex tend to focus on making sex safe and clean rather than on the enjoyment of sex and suggests that society perceives sex as dangerous. However, Nicky's perception of self is that she is sick, and will never not be sick, and so the implication is that Nicky should never have sex. Thus, the development of a sexual identity from a body that is HIV-positive is extremely challenging. Green (1994) supports this idea by describing HIV sexuality as occurring “within a hostile and frightening environment” (p. 136).

The participants' concern with sex's link to HIV and illness were twofold: concern about infecting others and concern about re-infecting themselves. Siphos stated:

- L: ok. Why is it [sex] dangerous? [...]  
S: when you sleep with a girl you could infect her with HIV...when you sleep with her  
T: ok he says because if you sleep with a girl you might infect her with HIV  
L: tjo. So do you worry about that?  
T: so then you worry about things like that?  
S: yeah (Siphos, 2, p. 13ish)

Siphos describes sex as dangerous because it could lead to him to infecting his partner with HIV. His use of the word "you" in "when you sleep with a girl you could infect her" is significant because it makes it clear that he is the one doing the action of infecting, as though the girl has no part to play in it. Thus, Siphos is taking sole responsibility for possibly infecting others.

This makes the self solely responsible for containing its own sense of badness in both internal phantasy and external reality (Ivey, 1990). Literature extensively describes people who are HIV-positive being concerned with infecting others (Green, 1994; Kelly *et al*, 2008; Rohleder & Gibson, 2006). The concept of being concerned with infecting others stands in contrast to HIV-related stigma which makes people responsible and blameworthy for their own infection (Deacon *et al*, 2009). For people who are HIV-positive it seems that the external reality of being able to infect others with HIV is introjected to say something about the self (Ivey, 1990; St. Clair, 2000). In this way, the possibility of infecting others confirms the participants' self-concept as bad and dangerous.

While concerned about infecting others, Nicky is more concerned about re-infecting herself:

- L: Do you worry about making other people sick?  
N: (*starts of speaking very softly but from "because..." gets loud again*)... sometimes I am but at the same time I'm not because if those people were... were responsible they shouldn't have been... doing it without a condom (Nicky, 2, p. 44)  
  
N: It's because like, ah, there was this book I've read, there was this girl... who, who was affected (*Lindsay nods because Nicky looks at her*) and she told herself that, I don't know where, where he, she don't know where (*seems to swallow on "where"*) she got it (*Lindsay nods because Nicky looks at her*) and she won't find out (*Lindsay nods because Nicky looks at her*) all she would do, she will spread it (*Nicky seems quite angry and with lots of emotion*)  
L: Sjo... Is that good? Bad?

N: It's a, it is bad [...] Because, eyoah... she might... she might harm herself, she might get five HIV poisons (*Nicky starts laughing*) [...] Ya or her, or her immune system might drop (Nicky, 2, p. 43)

Nicky softly admits that she does worry about infecting others. However, her tone then changes and she starts speaking louder in a way that is suggestive of anger. She states that if people were responsible then they “shouldn't have been... doing it without a condom”. Thus, for Nicky every individual is responsible for their own HIV-status. Her description of the girl in the second narrative is filled with repetitions of words and pauses. In addition, “Nicky seems quite angry” and emotional. When asked how she feels about the girl purposely spreading HIV Nicky again pauses and repeats words. This is suggestive of unconscious anxiety (Malan, 1979). Nicky's anger and emotions appear to stem from the fact that the girl “might harm herself, she might get five poisons”. Nicky seems to defend against the anxiety of this through the use of laughter (Lemma, 2003; Malan, 1979). Thus, for Nicky sex is dangerous for herself rather than others. This is consistent with her perception of others and the world as dangerous (see 5.2.2) and her internalisation of herself as vulnerable and easily hurt (see 5.3.1.1).

No literature can be found describing concerns about re-infecting oneself from the perspective of someone who is HIV-positive. However, Nicky's position does reflect an internalisation of HIV-related stigma's perception that each individual is responsible for their own HIV-infection (Deacon *et al*, 2009). In this way Nicky splits off her responsibility of possibly infecting others by externalising it onto her partners (Bateman & Holmes, 1995; Ivey, 1990; Segal, 1992). This suggests that Nicky is unable to bear the knowledge that, like her parents, she could be responsible for infecting someone else (Lemma, 2003; Malan, 1979).

Thus, for all three participants sex is bad, dangerous and scary. Green (1994) describes her HIV-positive participants' fear of sex. Like this research, her participants viewed sex, and their own sexuality, as dangerous (Green, 1994). McDougall (1995, in Hayes, 2012) states that sex is unavoidably traumatic, and so given the participants' perceptions of sex it would seem that this is even more so the case for these research participants. Hayes (2012) argues that sex is as much to do with enjoyment as it is with death. In this manner, the issues of HIV, of life, death, intimacy, acceptance and abandonment, are captured in sex (Hayes, 2012). This makes sex incredibly threatening for these vertically-infected HIV-positive adolescents.

The participants' perception of sex as dangerous, scary and bad means that the participants are going to protect themselves by being defended against sex and their own sexuality (Lemma, 2003). The implication of this is that the participants will not be able to relax in the transitional moment of sexually being with an other (Ivey, 1990; Winnicott, 1971). This is consistent with the participants' experiences of intimacy and self. It also means that the participants are unlikely to go through the stage of experimentation as is described by sexual identity theories (Eliason, 1995; Stiepe & Tolman, 2003; Worthington *et al*, 2002). It would appear that the participants have internalised and adopted the biopsychosocial influences in their microsocial context and culture (Worthington *et al*, 2002) that state that HIV and sex are dangerous together.

#### 5.4.2 Desire: The societal narrative

However, despite the vertically-infected HIV-positive adolescents' perceptions of sex as bad, dangerous and scary, the participants still expressed sexual desire. This was in terms of their own sexual desire but also an acknowledgement of others' sexual desires and the wider societal norm of sexual desire. In addition, all three participants wanted an intimate partner and children in the future. Thus, this theme captures the typical societal discourse regarding sex and sexuality (Bogaert, 2012).

In relation to the participants' own sexual desire, Sihle envisions having a honeymoon, as opposed to a wedding (Sihle, 2, p. 45). This is significant because a honeymoon is typically associated with being alone with an other and having sex. In Siphos drawing of a boy in Interview 2 (see Appendix N) he identified himself as thinking that "sex is right" (Siphos, 2, p. 8). He stated that the drawing was of himself, which suggests that he is in touch with his own sexual desire. Nicky expressed a curiosity about sex (Nicky, 1, p. 48). When asked why she would have sex with her boyfriend she stated:

... because I, I want to know him better (Nicky, 2, p. 36)

Thus, for Nicky there is something to be learned about an other through sex. Sex therefore refers to both a physical and an emotional intimacy, which is consistent with Hayes' (2012) concept of sex as being fundamentally about relationships.

From an object relations perspective, the participants' sexual desire, and desire for physical and emotional intimacy, can be understood as stemming from the participants' basic need to be in connection with others (Epstein, 1991; Ivey, 1990; Lemma, 2003). This is because sex represents the closest attainment of a total connection with an other. The participants' sexual desire is congruent with the assumption that human beings are inherently sexual (Bogaert, 2012; Freud, 1905; Hayes, 2012). However, the participants' desire, despite their perceptions of sex (see 5.4.1), is also reflective of Hayes' (2012) description of sexual desire as irrational. The focus on safe sex and HIV prevention though has resulted in a poverty of literature on the experience of having sexual desire from an HIV-positive body (Hayes, 2012).

The participants were also aware that other people have sexual desire and that sexual desire is a societal norm and expectation. This highlights the first assumption of theories on sexuality: that people have a desire to have sex and are expected to have sex (Bogaert, 2012). Siphos states that both men and women are expected to be sexually active (Siphos, 2, p. 33) and that this is reinforced through the media (Siphos, 1, p. 16). Sihle states that people have a choice as to whether they want to date or not, but that if they decide to date then they have to have sex (Sihle, 2, p. 42-43). Nicky demonstrates this assumption in the following extract:

- L: What do your friends think of you, that you don't want to have sex and you're not interested?
- N: (*Nicky starts giggling*) They, they, they... some of them they said I'm a lesbian, like – [...] Ya, they ask "are you normal?" (*Lindsay and Nicky laugh*). And then I was like "ya, I'm normal. It's like "no without that". (*Nicky and Lindsay laugh*)... And if, if some of my friends have pornographic on their phone, they said "do you want it?" Then I said "uh-uh", I said, "uh-uh" (*shaking head*).
- L: You don't even want to watch it, just –
- N: Uh-uh. I said "you are not normal" (*Nicky and Lindsay laugh*) [...] But my mum, most of the time (*Nicky laughing*), most of the time, she said, ah, you are 21, you are 21, now I am waiting for the boyfriend (*Nicky and Lindsay laugh*). She said "no, don't worry, just be free". She said "ah, I doubt you are straight!" (*Nicky looks at Lindsay and laughs*). I said "Ai, I am fine, I'm straight" (Nicky, 1, p. 52 – 53)

Nicky's friends, and her foster mother, expect her to have a boyfriend and become sexually active. Her lack of sexual desire has resulted in those around her thinking that Nicky is "a lesbian". They assume that she is not "normal" and insist that she cannot be "normal" without being sexually active. Nicky is therefore othered for not being interested in sex. However, Nicky thinks that their sexual desire is "not normal". Nicky's microsocial context (Worthington *et al*, 2002) actively encourages Nicky to become sexually active. This is in contrast to Sihle's and Siphos' microsocial contexts. Nicky laughs throughout the narrative

though, which unconsciously suggests that the pressure to be sexually active is more painful than Nicky is consciously admitting (Lemma, 2003; Malan, 1979).

Nicky describes people's perceptions of virginity as something that goes against the social norm (Nicky, 2, p. 53). This is to such an extent that Nicky stated:

- N: There was this day, ah, at school, we had a chat with my friends (*Nicky starts laughing*)... there when we talk about sex with my friends. And they said to me “you must (*Nicky laughs*), you must break it or, or your virgin, or your pussy will got rotten” (*Nicky and Lindsay laugh*) I said “no, that’s crazy”, they said “yes, you must break it” (*Lindsay and Nicky laughing*) I said “no, that’s crazy” (*quieter, seems sad*)
- L: And you really think something –
- N: Ya they said sometimes, one day you will be waiting for Mr Right and Mr Right took it and then ran away (*Nicky and Lindsay laugh*). He will run away (Nicky, 2, p. 54)

Nicky's laughter at the beginning of this narrative immediately suggests that Nicky is experiencing underlying anxiety (Malan, 1979). The use of the phrase “break it” is indicative of something painful, violent and unpleasant, which is possibly how Nicky perceives sex. Nicky's friends told her that if she does not lose her virginity her “pussy will got rotten” such that when she does eventually lose her virginity she will scare “Mr Right” away. This implies a self-image of her body as rotten, fermenting, self-destroying and repulsive. In addition, it supports the previous argument that Nicky believes that if she shows her true, whole self then she will scare others away with her badness, and ultimately be abandoned (see 5.3.1). The phantasy in this quote is that if Nicky does not use her body and her sexuality then her body will literally rot and disintegrate, thus making her even less desirable and likely to be loved as a whole object (Ivey, 1990; Lemma, 2003).

Therefore, all three participants are acutely aware of society's expectation for sex and sexual desire. This awareness possibly acts as a defence by projecting and externalising their own sexual desire onto others (Lemma, 2003; Segal, 1992). In this way the participants protect their sense of self from the badness of sex (see 5.4.1). However, the participants are in a difficult position as society's expectation of sex is in direct conflict with the need to prevent further HIV-infection.

All three participants described wanting a partner in the future. Siphon wants to get married. Sihle wants to go on honeymoon. Nicky, however, states that she does not want to get

married because marriages do not last (Nicky, 1, p. 53-54). However, this does not stop Nicky having an idea of, and desire for, an intimate relationship:

- N: Ah... I just thought about people being in love, ya. When talk about sexuality  
L: Ok. So you think about people who are in love, they love each other so much  
N: Ya  
L: And they've loved-  
N: They share everything (Nicky, 2, pl. 16)

Nicky states that she associates sex with “people being in love” and sharing everything. This represents a very intimate, trusting relationship in which the self is shared safely with an other. Siphon describes sex as a similar intimate relationship of knowing an other (Siphon, 2, p. 10ish). These concepts of sexuality represent an idealised kind of sexuality (Segal, 1992). The badness of sex is split off such that a part of sex can be tolerated (Bateman & Holmes, 1995; Ivey, 1990; Segal, 1992). This allows sex to not be a completely hated object (Lemma, 2003).

However, such idealisation of sex is psychological unattainable. Firstly, Nicky and Siphon view others as bad and so do not trust others enough to reveal their whole selves (see 5.2.2). Secondly, all three participants expect to be rejected following their disclosure of their HIV-status because their perception is that their whole selves cannot be accepted and loved (see 5.3.1.2). In this way, the participants' experiences of intimacy and self have impacted negatively on their experience of sex and sexuality.

Nicky herself says that she does not think that she will ever find a partner who completely understands, loves and accepts her. She therefore hopes for an intimate relationship not with a sexual partner but rather with her future child. Nicky stated:

- L: So like if we had... if you could plan your dream of how, how your life is going to go (*Nicky smiling*) with having a kid, how will it happen? What will it look like?  
N: I would be a single mother [...] It will be fine if it will be just me and my kid only (Nicky, 2, p. 32 – 33)

Nicky's dream is that she will be in a committed relationship with a boyfriend, have sex with him after two years so that she can fall pregnant, and then he leaves enabling her to be a single mother. She states that she will be “fine” if it is only her and her child. This “fine” is significant given how insistent Nicky usually is that she is not “ok” and never will be. This suggests that, in accordance with object relations theory, Nicky's greatest desire is for a

connection with an other (Epstein, 1991; Lemma, 2003). Nicky's perception is that she cannot experience this with adults (see 5.2.1.2). In addition, an intimate relationship with her child ensures that sex never threatens the relationship. Thus, Nicky has found a way of satisfying her need for intimacy and connection with others while splitting-off sex (Bateman & Holmes, 1995; Ivey, 1990; Segal, 1992).

Nicky statement that "it will be fine if it will be just me and my kid only" is significant in terms of the oedipal complex (Hinshelwood, 1994). It suggests that Nicky does not seem to be able to hold triad relationships and instead needs dyad relationships (Hinshelwood, 1994; Lemma, 2003). This idea is supported by her current relationship with her foster mother, which has quiet a romantic tone to it and involves everything that Nicky says is part of a good sexual relationship: talking, joking, hand holding and no sex. Thus, once again, Nicky's need for intimacy is being satisfied from a relationship in which the threat of sex can never enter into the relationship. Nicky's struggle to negotiate triadic relationships suggests that she experiences persecutory anxieties (Bateman & Holmes, 1995; Hinshelwood, 1991) and does not see herself as separate from others (Bateman & Holmes, 1995; Lemma, 2003). This explains her concern with others' lack of respect for boundaries (see 5.2.3).

Although Siphos wants a son (Siphos, 2, p. 22), he and Sihle both expressed ambivalence about having children. When asked if it is good to have children Siphos stated:

It's good for other people who treat them well [as in take care of them] (Siphos, 2, p. 22)

The following dialogue occurred with Sihle:

- L: you look sad  
S: no I don't want children yet  
T: you don't want them?  
S: no (shakes head). I don't want them yet [...]  
T: but like then when you're married to your husband right, wouldn't you want them then either?  
S: no I want them (Sihle, 2, p. 47)

For Siphos it is good to have children only if the adults in their lives provide for them and do not abandon them. Sihle is sad while discussing her desire to have children and states that she does not want children "yet". When explored further she stated that this sadness was due to her anxiety about possibly infecting her children with HIV (Sihle, 2, p. 48-49). Long (2009) found similar concerns in her research. Thus the perception that others abandon (see 5.2.1.1)

and that the self is infectious and bad (see 5.3.1.2) complicates Sihle and Siphó's desire for children.

All three participants told narratives that conformed to society's discourse around sex and sexuality. The participants described having their own sexual desire. In addition, the participants reflected an awareness of others' sexual desires and society's expectation of sexual desire, and a desire for an intimate partner and children. The participants' own sexual desire goes against perceptions of sex as bad (see 5.4.1) and can be understood as stemming from the basic human need for connection with others (Epstein, 1991; Lemma, 2003). However, despite the participants' sexual desire and awareness of the expectation to have sexual desire, the participants still do not want to have sexual desire.

#### 5.4.2.1 Desire not to have desire: The HIV narrative

Given the participants' perceptions of sex and sexuality (see 5.4.2), it is consistent that all three participants described not wanting to want to have sex. The desire not to have desire goes against, and is layered on top of, society's narrative of sex and sexuality (see 5.4.2). Thus, the participants are torn between two conflicting perceptions of sex and sexuality.

The participants described ambivalence around their sexuality. Siphó describes having sexual desire but feeling that he should not (Siphó, 2, p. 29-30). Nicky repeatedly states that she is not ready for sex, but when questioned about this she claims that she will never be ready (Nicky, 2, p. 47). Sihle admits that she sometimes thinks about having sex but ultimately decides that she should not because "it is wrong" (Sihle, 1, p. 6).

When asked why people have sex Siphó stated:

It's liking things (Siphó, 2, p. 27)

The English translation of Siphó's response does not adequately capture the meaning in isiXhosa, but the Xhosa response implies that people should not like or do sex. It implies that sex and sexual desire says something bad about a person's identity, for example that the person is forward, rude, cheeky and arrogant. Thus, sexuality has become a moral rather than biological matter for these participants (Hayes, 2012). In this way the participants have internalised stigma's portrayal of HIV and sex (Deacon *et al*, 2009; Hayes, 2012; Ivey, 1990).

Sex is further complicated for these participants by its complexity (Burman, 2008; Epstein, 1991; Hayes, 2012; Morgan, 2012; Worthington *et al*, 2002). All three stated that homosexual sex is possible and suggested that it is acceptable. This suggests that the participants do not subscribe to the construct of heteronormativity as described by Worthington *et al* (2002). However, Sihle stated:

It's also scary because it's not allowed for girls to do that (Sihle, 2, p. 31)

While Sihle acknowledges that girls can have sex with girls, she states that “it’s not allowed”. This demonstrates an awareness that society has rules concerning who can have sex with whom (Mohr, 2002; Worthington *et al*, 2002).

In addition, the idea that masculinity is associated with sexuality, and specifically heterosexuality (Eliason, 1995; Lindegger & Quayle, 2009; Yarhouse & Tan, 2004), was narrated by Sihle and Siphso. Nicky did not mention it other than to say that men are expected to have more than one partner. When asked to draw sexuality in Interview 2 Sihle drew round circles (see Appendix J). When asked about the drawing Sihle stated:

It looks like sperm (Sihle, 2, p. 19)

Thus, when asked to draw sexuality Sihle drew something representative of a man’s role in sexuality. While this is possibly a defence to remove herself from sexuality (Lemma, 2003), it could also be argued that Sihle views sex as masculine and intimately connected with the inequality of patriarchy. Such a concept is supported by Jewkes (2009) and Lindegger and Quayle (2009). This makes sex even less safe in phantasy for Sihle (Segal, 1992). Siphso stated:

T: is it allowed for men to not have sex?  
S: ...*(silence)* no (Siphso, 2, p. 32)

Siphso thus states that it is not acceptable for men not to have sex, a notion that fits with the literature on hegemonic masculinity (Eliason, 1995; Lindegger & Quayle, 2009; Yarhouse & Tan, 2004). Siphso’s defensive silence prior to answering suggests that the demand for him to be sexually active is a source of anxiety for him (Lemma, 2003; Malan, 1979). Siphso seems to try to conform to the demands of masculinity and act like the other boys his age (Siphso, 1, p. 47). However, following his drawing in Interview 2 (see Appendix N) and his realisation

that sex can have negative consequences, Siphon for the first time went against his perceived demands of masculinity and admitted that he does not want to have sex (Siphon, 2, p. 12). This suggests that for Siphon the 'badness' of sex is more powerful than conforming to the demands of hegemonic masculinity.

Lastly, part of what makes the participants' own sexual desire so undesirable and conflicted is that sex is so difficult to see as a whole object for these participants (Hinshelwood, 1991). This could be due to the threatening nature of sex for these participants. For example, Nicky states that sex makes babies but that it is also dangerous (Nicky, 2, p. 21). Sihle literally splits sex into its different, manageable parts in her drawing in Interview 2 (see Appendix J). Sihle stated:

- T: So you have two parts of you when, like when it comes to sleeping with someone right? You have the part that wants to, and that part that's afraid, or you don't want this person to get sick too?
- S: (*Sihle looks at the bottom of the roll and moves it so that it is horizontal and nods*) I have that part that's afraid (Sihle, 1, p. 39)

Between her desire to have sex and her fear of sex Sihle focuses on her fear. The difficulty of holding sex as a whole object is captured in the following extract:

- T: she's saying it sounds like you're trying to bring the fact that sex is supposed to be nice right, and then the fact that sex is scary, maybe you're trying to bring them together into one thing, but you can't because on the one hand it's nice and then again on the other hand it's scary. Is it like that?
- S: yeah (nods) [...] ...I'm thinking that it's like what you're saying because it's true (Siphon, 2, p. 14ish)

Siphon's pause denotes a tangible thinking about and identification with what the translator has said to the extent that Siphon agrees twice with the translator. It is thus difficult for the vertically-infected HIV-positive adolescents to view sex as a whole object (Hinshelwood, 1991). Therefore, the participants appear to experience paranoid anxieties with regards to sex and sexuality (Bateman & Holmes, 1995; Hinshelwood, 1991) and make use of defensive splitting in order to make sex safer (Bateman & Holmes, 1995). Thus the lived experience of being a sexual being who is HIV-positive is difficult to understand in its complex entirety (Hayes, 2012). This is consistent with the "'beyond language', 'beyond speech'" unknowingness of sex (Hayes, 2012, p. 155).

All three participants have sexual desire and want children and an intimate relationship. This is consistent with society's narrative concerning sex and sexuality which assumes that people are sexual and want to be sexually active (Bogaert, 2012). However, it is conflicted for the participants as none want to have desire. Sex is complex because the participants have to negotiate their HIV-positive identity with society's expectation that they be sexually active, in addition to the myriad of other rules concerning sex like heteronormativity and constructs of masculinity. Therefore, the participants' lack of sexual desire goes against society's expectations. This places the participants in a very difficult position with regards to sex and sexuality.

#### 5.4.3 Sex threatens boundaries

It was previously discussed that part of sex's threat for this research's participants was its link with HIV-infection (see 5.4.1). The analysis revealed that the participants' concern with sex additionally lies in its threat to boundaries. This is consistent with the participants' persecutory anxieties. Sex by definition involves the coming together of two naked bodies in arguably one of the most intimate ways that two people can be together. It involves blurring the physical and emotional boundaries between people. This is a blurring of both the external reality of HIV and the internal reality of unconscious phantasy (Hayes, 2012). Thus, in line with how the participants experience intimacy (see 5.2), the danger of sex lies in its lack of boundaries.

Sihle's drawing from Interview 2 (see Attachment J) captures the concern with the lack of boundaries that sex posits:

- T: Uhm. It looks like it's circles. You know circles right? (*nods*) She says it looks like circles so could you tell us what your circles are?  
S: Because I don't want it moving across. The colouring (Sihle, 2, p. 12)

This quote is significant because it shows that when Sihle was asked to draw what sexuality looks like she drew something that does not "move across" or mix. Sihle's projection was to draw something that highlighted the boundaries and borders of sex (Lemma, 2003).

Nicky and Siphon particularly refer to the lack of emotional boundaries with regards to sex. Neither participant wants to disclose their HIV-status to their sexual partner. Siphon stated:

- T: she's asking why—she says she knows that we spoke about it last week but could you tell her again why you—you wouldn't tell her? Your girlfriend
- S: because the moment I tell her, maybe she'll go to her friends and gossip about me that I have HIV (Sipho, 2, p. 16)

Sipho's use of the phrase “the moment I tell her” suggests that his perception of his girlfriend is of her betraying his confidentiality as soon as he discloses his status. It is as if he cannot imagine her keeping his confidentiality at all. He states that his girlfriend will “go to her friends and gossip” about his HIV status. The concern with disclosure has been extensively documented in literature (Deacon *et al*, 2009; Fernet *et al*, 2007; Green, 1994; Kang *et al*, 2008); however this seems to be related to fears of being actively stigmatised against rather than fears of the other betraying the confidentiality.

Nicky's and Sipho's refusal to make themselves emotionally vulnerable by disclosing their HIV status suggests that the participants do not trust others to keep the boundary of their confidentiality. This is consistent with their object relations that others cannot be trusted (see 5.2.2). Thus the participants' experience of intimacy has negatively impacted on their negotiation of sex and sexuality.

Sex also threatens boundaries physically. Nicky stated:

- L: Mmm. Why don't you want to do anything physical?
- N: Whew, I don't know but ah, I just, I'm not comfortable (*Nicky gestures over her body*)... with boys
- L: With physical or with boys
- N: Ya... because ah, there was this girl at school... she was so close with her boyfriend... then they, they did sex [...] And there was a camera (*Nicky looks at the camera*)
- L: Gee, so he recorded her?
- N: Ya. They made a pornographic... [...] And the video was all over the school
- L: Yoah, that's
- N: So terrible (Nicky, 1, p. 46)

Nicky states that she is “not comfortable” while gesturing to her body, suggesting how uncomfortable Nicky is with her body in relation to others and sexuality. This is consistent with Nicky's sense of self, body (see 5.3.1) and others (see 5.2.2). Thus the experience of intimacy and self has negatively impacted on Nicky's negotiation of sex and sexuality. Nicky then articulates a narrative about a girl at school who was “so close with her boyfriend” but was video recorded having sex. The video was subsequently distributed “all over the school”. This narrative describes an emotional and physical betrayal: the girl trusted her boyfriend but

he recorded them having sex and then exposed their intimacy and nakedness to the entire school. Nicky describes this as “so terrible”. The physical loss of boundaries possibly unconsciously reminds Nicky of her grandmother’s rape and her already discussed sense of personal vulnerability (see 5.3.1.1). Nicky’s sense that physical boundaries can be violated cannot help but be internalised (Ivey, 1990; St. Clair, 2000) and so further exacerbate the self’s sense of vulnerability.

For Nicky, it appears that once a couple has sex all boundaries are lost. This is because from Nicky’s perspective people cannot be trusted to respect boundaries. Therefore, it is possible that for Nicky sex can only be good in theory, never in practice. The following dialogue occurred with Nicky:

- L: So as soon as sex comes it becomes a bad relationship?  
N: Ya, it will. Because once you have sex, the person might think... might expect more of you, or think that [...]  
L: Like what?  
N: Like doing it  
L: Oh, like you need to have sex more often?  
N: Ya, more often, ya, like ah, do it without a protection, all that stuff or just cheat on him (Nicky, 2, p. 57 – 58)

For Nicky sex immediately makes a relationship bad. This is because the other will “expect more” by either expecting sex more often, wanting to have unprotected sex or wanting to have more sexual partners. In other words, from Nicky’s perspective if sex occurs once, the other will think that they can have everything constantly. It is possible that Nicky’s sense of self as separate from others is so fragile that she feels that she will not be able to maintain her sense of separateness following the intimacy of sex (Bateman & Holmes, 1995; Lemma, 2003) and consequently experiences persecutory anxieties of the self being absorbed and engulfed by the other (Lemma, 2003). From an object relations perspective this is consistent with Nicky’s failure to resolve the oedipal complex (Bateman & Holmes, 1995). It is argued that Sipho and Sihle experience the same persecutory anxieties (Hinshelwood, 1991).

For all three participants sex is physically and emotionally threatening. Sex makes explicit the external reality of possibly infecting others or re-infecting oneself. In addition, it prompts the phantasies of the self being engulfed and harmed through intimacy. Thus, sex is threatening because of its lack of boundaries between the participant and other. This is captured in the fact that all three participants linked sex with sexual harassment and rape,

possibly because the lack of choice involved in rape mirrors the participants' lack of choice in their HIV status.

Nicky speaks about how her Gran's rape impacted on her concept of sex:

N: Ah, it impact a lot because... in other cases there are people who don't understand what "no" means [...] (*Nicky speaking very softly*) It's really hard (*Nicky sniffs and wipes her nose*)

L: Ya, it makes sex really scary... And especially then because it lead to her becoming HIV positive, hey?

N: Ya (*sounds like she might cry again*) (Nicky, 2, p. 69 – 70)

Nicky's pause, her soft tone of voice, and emotional state during this dialogue unconsciously communicates how deeply she was affected by her Grandmother's experience. The experience meant that Nicky grew up with an idea that others "don't understand what 'no' means" and do not respect boundaries. In addition, this violation of boundaries can have very negative consequences to the extent that sex can be used as a weapon. This is consistent with her use of the phrase "break it" previously discussed (see 5.4.2).

It is significant that in Interview 2 rape and sexual harassment were mentioned very early on by both Nicky and Siphon. This is suggestive of how intimately linked rape and sex are for the participants. Siphon stated:

Sex is a sexual abuse to person under 21 years (Siphon, 2, p. 11)

Siphon is clearly aware that there are times when sex is inherently wrong, for example when an individual is underage. It is unclear though whether he is referring to the act of sex or sexuality. However, he did not want to talk in more detail about this. Siphon's statement raises Burman's (2008) concerns about how sexuality is constructed in relation to children.

Sihle discussed rape more in terms of the gender inequality that exists between men and women (Jewkes, 2009; Lindegger & Quayle, 2009). She stated that men cannot be trusted and that this dishonesty hurts sexuality more than women's dishonesty. When asked why she stated:

S: ...because they [boys] are evil. They could do that, and want to sleep with you without a condom, force you, and beat you [...]

T: could you beat them?

S: no i don't have the strength

T: no she doesn't have, she doesn't have the strength of a boy

- L: oh. So then boys are more powerful than girls?  
T: so then boys are more powerful than girls?  
S: yes (nods) (Sihle, 2, p. 28)

For Sihle boys “are evil”. This is because boys can “force” sex, make sex happen without condoms and “beat” girls. In this sense boys are more powerful than girls. Men are described as not respecting boundaries and taking whatever they want by force. This is consistent with constructs of hegemonic masculinity as forcing sex and having an “uncontrollable sex drive” (Jewkes, 2009, p. 36) and possibly adds to Sihle’s negative feelings about sex.

The phenomenon of forced sex is not something that is unique to females though. Siphos is also forced to have sex:

- T: so then you feel like you have to have sex even if you don’t want to?  
S: yes (nods) (Siphos, 2, p. 35ish)

Siphos is forced to have sex by the demands of hegemonic masculinity (Jewkes, 2009). This is because the constructs of hegemonic masculinity require men to be sexually active in order to be considered ‘men’ (Jewkes, 2009; Lindegger & Quayle, 2009). Siphos is therefore in a very difficult place where he is trapped between the bullying, demanding requirements of both patriarchy and HIV. However, hegemonic masculinity reduces his means of coping with this as he is not allowed to show vulnerability (Lindegger & Quayle, 2009).

#### 5.4.3.1 Put in boundaries to make sex safe

Due to the threatening nature of sexuality and the social requirement of being sexually active, all three participants described putting boundaries in place to make sex safer (Lemma, 2003; Winnicott, 1971). These boundaries take the form of condoms and having rules about relationships. In addition, the participants use a further two measures to neutralise the threat of sex: the participants will not disclose their HIV status prior to having sex (see 3.4.3.2) and the participants cut off or remove themselves from sexuality (see 3.4.3.3).

All three participants argued for the use of condoms. This is reflective of society’s focus on condoms and their ability to make sex “sanitised” (Hayes, 2012, p. 153). Sihle and Siphos stated:

- T: so you said sex is wrong right? It's scary. So then what is it like to have a sexuality that thinks about sex but you'd said sex is wrong, is scary—is scary?  
 S: I think that it's scary but you have to do it but then use a condom (Sihle, 2, p. 42)

If you are not using condom you will be pregnant or die to HIV and AIDS (Sipho, 2, p. 21)

Sihle states that “you have to do it”, which suggests that she feels obligated to have sex. However, this seems to be made possible for her through the use of condoms. For Sipho condoms make sex safe by preventing HIV infection and pregnancy. The condom is obviously linked to the need to prevent HIV-infection; however it is possible that there is something deeper and more unconscious about condoms for the participants. Condoms seem to not only be a physical barrier between the participants and their partners but also a symbolic barrier that makes sex safer both in phantasy and in external reality (Lemma, 2003; Segal, 1992). In addition, condoms allow Sipho to comply with hegemonic masculinity constructs that require him to be sexually active (Sipho, 2, p. 33).

In addition to condoms, Nicky has created rules for herself concerning relationships. These are conditionals which in her mind seem to make her and sex safer. Firstly, she has decided that she will not have sex with someone unless they have been dating for two years.

Secondly, Nicky stated:

- N: It will depend, but in public like, if we are, ya, we are in a car, we can kiss [...]  
 L: Why? (*Nicky starts laughing*) Or tell me your thoughts there, why is it ok in public?  
 N: Ah, no (*Nicky laughing*). Ah, because in public... we, we can't do sex, in public, ya  
 L: Oooh  
 N: That's what I -  
 L: That's very clever (*Nicky laughs*). Ya?  
 N: Ya. And he won't expect more [...] on a kiss, ya. He just think that no, we are in public (*waving palms in front of her body*) (Nicky, 2, p. 34 – 35)

Nicky states that she is happy to kiss her boyfriend as long as they are in public because he cannot “expect more”. This quote suggests that Nicky has a desire to be sexually intimate, but only if she can trust that nothing more will be expected of her. By implementing boundaries Nicky reinforces the boundaries between the self and the other and therefore feels safer from the threat of engulfment that intimacy poses (Abraham, 2007; Ivey, 1990; Lemma, 2003; Winnicott, 1971).

#### 5.4.3.2 Will not disclose status before sex

Nicky and Siphon both declared that they would not disclose their HIV-positive status to their partner prior to having sex (Nicky, 2, p. 44; Siphon, 1, p. 49). Siphon did however later state that he would tell his wife, but only once they were married. Sihle, in contrast, said that she would disclose her status prior to having sex, but she expects to be rejected following this (see 5.2.2). Nicky's and Siphon's resistance to disclosing, and Sihle's expectations of being rejected following disclosure, suggest that disclosure is extremely difficult for these adolescents. The participants' attitudes to disclosure are consistent with Nicky's and Siphon's perception of others as bad (see 5.2.2) and all three participants' perception of their whole selves as unlovable (see 5.3.1.2).

Siphon stated:

- T: Telling—telling people you have HIV is difficult?  
S: (*Silence for about 10 seconds*)  
L: is that a yes? No? Sometimes?  
T: is it difficult or not difficult or difficult sometimes?  
S: it's difficult (Siphon, 1, p. 50ish)

Siphon's silence unconsciously reveals that contemplating disclosing his HIV-status is anxiety provoking for him (Lemma, 2003; Malan, 1979). This is supported by his answer that disclosure is "difficult", as opposed to "sometimes difficult". Concerns about disclosure have been extensively documented in the literature (Fernet *et al*, 2007; Ferrand *et al*, 2010; Kelly *et al*, 2008). Deacon *et al* (2009) describe disclosure rates as being negatively influenced by HIV-related stigma. Kang *et al* (2008) state this to the extent that some HIV-positive adolescents abstain from dating in order to avoid having to disclose their HIV-positive status.

It appears that disclosure is challenging because it represents a removal of another boundary for the participants, which in turn adds to the sense of vulnerability of the participants' selves. Disclosing their status requires the participants to trust that the other will not betray their confidentiality. This is unlikely though given the participants' perception of others (see 5.2.2) and how vulnerable the participants already feel (see 5.3.1). Thus, the participants allow themselves to feel safer by defensively ensuring that this boundary is at least maintained (Lemma, 2003). Therefore, this is an adaptive defence (Lemma, 2003).

Nicky, however states that the fact that she was infected vertically makes it slightly easier for her to disclose her status. This is because HIV-related stigma portrays vertical-infection as perceived as desirable (Deacon *et al*, 2009). Nicky stated:

- L: So it is very important for you then that you became HIV positive from birth?  
N: Ya, it is because in other cases there are people who, who got it sex [...] They, they don't share it with [tell] their partners [...] Ya, and –  
L: So they don't tell their partner?  
N: Ya  
L: Ok  
N: And there are people who are, who born with it, and they share it with their partner, some of them they understand that but others they think that “no, you are lying” (Nicky, 2, p. 61 – 62)

Nicky states that people who acquire HIV through sex do not disclose their status to their partners, while people who are vertically-infected do. The difficulty is though that some partners “understand” and others do not. “Understand” here possibly means that by knowing that Nicky is vertically-infected her partner will also know that she is not to be blamed for her infection (Deacon *et al*, 2009). Thus, disclosure is additionally risky because the other might put her in the same ‘blameworthy’ category as those who are horizontally or behaviourally-infected (Deacon *et al*, 2009).

By Nicky and Sipho not disclosing their HIV-status to their partners prior to sex, both are removing the choice of the other to knowingly consent to having sex with an HIV-positive person. Therefore, Nicky and Sipho are externalising their own lack of consent concerning their acquirement of HIV (Ivey, 1990; Segal, 1992).

#### 5.4.3.3 Cut off or remove self from sexuality

The final measure that appears to be used by the participants to protect themselves from the badness of sex is cutting their sexuality off from themselves or removing themselves altogether from sexuality. Green (1994) identified a similar response, in the form of the decision to be celibate, in her research with horizontally-infected HIV-positive adults. This requires the use of splitting (Segal, 1992). While this is a protective defence (Lemma, 2003), it ultimately results in splitting the self (Segal, 1992). It supports the argument that the participants are living as part objects (Ivey, 1990).

All three participants did not include anything sexual in their drawing from Interview 1 (see Appendix I; K & M). This is significant given that sexuality was specifically referred to as part of what the participants could draw. When asked about where her sexuality was in the drawing Sihle's body language conveyed the following:

*(Sihle tilts her head to the side and takes a while to answer; when she speaks she shrugs her shoulders slightly) ...I couldn't draw it (Sihle leans her head forward and looks like she might bite her drawing but maintains eye contact with the Translator) (Sihle, 1, p. 13)*

While Sihle says that she could not draw her sexuality, her body language suggests that in phantasy Sihle literally wants to bite and destroy her sexuality (Segal, 1992). This is an example of Klein's understanding of aggressive impulses (Segal, 1992). Sihle appears to cope with this aggression by splitting-off her sexuality. She describes the drawing that she did for Interview 2 as sperm, yet when asked if there was an egg for the sperm she said that there was not (Sihle, 2, p. 20). She therefore splits femaleness off from sexuality, such that a sexual togetherness cannot occur (Segal, 1992).

All three participants remove themselves from sexuality. Sihle has never had a boyfriend (2, p. 39), and is sexually inactive. While Sipho has had girlfriends, he is not sexually active (Sipho, 1, p. 48ish). Nicky does not like boys (Nicky, 1, p. 43) and repeatedly reports in her interviews that she does not like to talk or think about sex (Nicky, 2, p. 12-13; 40; 41). Neither Sihle nor Nicky are even curious about what sex feels like (Nicky, 2, p. 41-42; Sihle, 2, p. 41). This is to such an extent that Nicky describes the following when she was in a relationship:

- N: Every time if, if he came close to me I'd just (*gestures with her hands that she would keep him away*)...
- L: You'd move away?
- N: Move back, ya [...]
- L: So you actually, you want more like a friend
- N: Ya (Nicky, 1, p. 45)

In the above narrative Nicky literally recoils from sexual touching and sexuality, implying that she only wants a plutonic relationship. This is supported by her description of a good relationship as something that does not involve sex (Nicky, 2, p. 57; see 2.4.1).

In Siphos drawing for Interview 2 (see Appendix N), after much resistance, Siphos stated that the drawing was himself and that it represented sexuality and sex being “ok” (Siphos, 2, p. 7ish). However when asked further about this he was unable to answer:

- T: what made you draw Siphos?  
S: ...[silence]  
L: you’ve been quiet for a very long time. I’m wondering why  
T: she says you’ve been quiet for a long time and she’s wondering why  
S: ...[silence]  
L: what you thinking?  
T: what are thinking?  
S: ...[silence]  
L: this seems like it’s very difficult. Is it difficult?  
T: she says it seems like this is difficult. Is it difficult?  
S: (nods) (Siphos, 2, p. 8ish)

Siphos resistance to answering suggests that following writing about sex and realising that sex can have bad consequences, he no longer wants to identify himself with or wants to have sex (Siphos, 2, p. 12ish). Siphos therefore unconsciously tries to remove himself from sex in the same way as he attempts to remove himself from the conversation by being silent (Lemma, 2003). He also removes himself from sex by stating that:

...sexual—sex is not right for a person who’s—who’s fifteen and hasn’t reached twenty one (Siphos, 2, p. 11ish)

This has the benefit of giving himself permission not to have sex until he is twenty-one. In this manner, he is able to resist the demands of hegemonic masculinity (Lindegger & Quayle, 2009).

In the attempt to destroy, split off sexuality or remove the self from sexuality, the participants appear to be attempting to project their sexuality such that it is separate from themselves (Lemma, 2003). This does not mean that the participants are not sexual beings or do not have sexual desire (Klein, 1932; see 5.4.2). Rather it means that sexuality is so threatening for the participants that the participants cannot hold it within their senses of self. Sex is so threatening because of its link to HIV-infection (see 5.4.1) and its lack of boundaries (5.4.3). In addition, the participants’ experience of intimacy makes intimacy of any kind, including sexual intimacy, threatening either for the self or the other (see 5.2.2). Lastly, the participants view their selves as bad, dangerous, sick and unlovable (see 5.3.1) and as such are unable to involve their bodies and selves in sexuality.

The participants' experience of persecutory anxieties and the self as a part object (Ivey, 1990) necessarily impacts on the participants' experience of intimacy and sex. From a Kleinian perspective, in order for the participants to be part of a good relationship, it requires that the participants be known as whole objects (Hinshelwood, 1991). However the participants do not believe that they can be loved and accepted as whole objects and therefore have two choices: either present themselves as part objects and be loved or present themselves as whole objects and not be loved (Segal, 1992).

### 5.5 Conclusion

This chapter has outlined and discussed the findings of this research. It has identified three major themes that influence each other: how the participants experience intimacy, how the participants experience their sense of self, and lastly how the participants experience and perceive sex and sexuality. Ultimately, the analysis revealed that participants' experience of intimacy impacted negatively on their sense of self and therefore on their experience of sex and sexuality. It was consistently found throughout the analysis that all three participants experience persecutory anxieties of annihilation. Therefore the analysis found that the lived experience of these vertically-infected HIV-positive adolescents is extremely anxiety provoking.

## **CHAPTER 6: Conclusion**

This research has explored the in-depth, lived experience of being a vertically-infected HIV-positive adolescent from a psychodynamic, object relations perspective. It focused specifically on how these adolescents experience intimacy, sex and sexuality in relation to their HIV status. Six psychoanalytic research interviews were conducted with three purposively sampled vertically-infected HIV-positive adolescents from Grahamstown. These interviews were analysed using a psychodynamic framework and the findings presented using IPA. The analysis identified three master themes: how the participants experience intimacy, how the participants experience self, and how the participants experience and perceive sex and sexuality.

### **6.1 Summary of findings**

The research participants' experience of intimacy appeared to be predominantly challenging. All three participants presented narratives of not being understood and known by others. It appeared that the dominant attachment figures in the participants' lives were either unwilling to acknowledge the difficulties of living with HIV or only able to see the participants for their HIV-positive status. This seems to have resulted in the participants struggling to find a transitional space in which to meet others (Aitken, 1002; Ivey, 1990). This implies that the participants struggle to differentiate between internal and external reality and have a sense of themselves (Ivey, 1990; Winnicott, 1971).

All three participants linked their HIV status with their mothers. In this sense, the participants' internal phantasies of being hurt by their mother (Segal, 1992) has become an external reality (St. Clair, 2000). Significant was that Siphon and Nicky's parents have passed away. This represents a permanent abandonment such that others cannot be trusted to be constant objects (Bateman & Holmes, 1995). Siphon and Nicky appear to have defended against the pain of this by internalising HIV-related stigma (Deacon *et al*, 2009; Lemma, 2003) and displaying significant anger and blame towards their parents. Siphon and Nicky's current attachment figures, their foster mothers, appear to be an improvement on their early attachment figures; however, they still appear to confirm the participants' previous experiences of intimacy (Segal, 1992). Siphon and Nicky narrated their foster mothers as not understanding the participants, betraying the participants by not disclosing their HIV-status to

the participants immediately, colluding with the demands of HIV and not providing a positive male attachment figure. In phantasy this appears to confirm for Siphon and Nicky that others cannot be trusted (Bateman & Holmes, 1995).

Sihle, in contrast, has not lost her mother. She therefore seems to defend against the pain of her mother having infected her with HIV by cutting off any negative feelings that she has towards her mother, thus allowing her mother to remain a good object (Bateman & Holmes, 1995; Ivey, 1990; Lemma, 2003). Sihle's mother also disclosed Sihle's HIV-positive status to her daughter the first time that Sihle asked why she was taking medication. This has enabled Sihle to experience a more trusting space with an other.

The participants' experiences with the dominant attachment figures in their lives necessarily impact on their perception of the world and others (Andersen & Przybylinski, 2012; Segal, 1992). Siphon and Nicky appear to perceive others and the world as bad, untrustworthy, uncaring, judgemental, gossiping and abandoning. This is possibly an externalisation and projection of the participants' own sense of badness (Bateman & Holmes, 1995). However, it has resulted in the world and others being perceived as too bad and dangerous to be safely intimate with. Sihle, on the other hand, appears to have internalised her mother's and the world's badness by cutting off her negative experiences with others (Ivey, 1990; Klein, 1952). However, this still results in intimacy being perceived as dangerous because for Sihle it will harm the other. This perception of intimacy as dangerous has resulted in narratives of isolation from all three participants.

The danger of intimacy seems to be exacerbated by the lack of boundaries in the participants' lives. All three appear to perceive others as not respecting boundaries and expecting more than the participants are willing to give. From an object relations perspective this is a terrifying position in which to be and suggests that the participants experience persecutory anxieties of annihilation (Bateman & Holmes, 1995; Hinshelwood, 1991; Lemma, 2003; Segal, 1992). The participants seem to defend against this terror by either artificially creating boundaries for themselves or making use of splitting (Bateman & Holmes, 1995; Segal, 1992).

However, despite the participants' challenging experiences of intimacy, all three participants still demonstrated a desire for intimacy. The participants narrated a desire for togetherness,

understanding, acceptance and trust. This is consistent with the object relations' premise that human beings' most basic need is to be in connection with others (Epstein, 1991; Ivey, 1990).

The participants' experience of intimacy, coupled with the meaning that the participants attached to HIV, impacted on their experience of self (Abraham 2007; Ivey, 1990; Thomas, 1996). All three participants presented HIV as a dominant part of their sense of self. It appears that the participants have internalised and identified with their HIV-positive status such that their self and their HIV cannot be separated (Ivey, 1990). However, in line with research the participants recognise HIV as imminent death (Hayes, 2012; Sontag, 1991, in Rohleder & Gibson, 2006). Therefore the participants seem to identify their self with death too. The participants are thus living with a self that is under constant threat of death, engulfment and annihilation (Bateman & Holmes, 1995; Hinshelwood, 1991; Lemma, 2003; Segal, 1992). This suggests that the participants experience persecutory anxieties (Lemma, 2003).

The participants' identification with HIV seems to be reinforced by their experience of their bodies as sick. This is signified at bare minimum by the fact that all three participants take medication every day. Siphso does not describe himself as physically sick but this is possibly as a way of conforming to the demands of hegemonic masculinity (Lindegger & Quayle, 2009). In contrast, Nicky and Sihle describe their bodies as weak and fragile. It is possible that this perception of the body is internalised to the extent that the self is perceived as just as vulnerable (Bardhan, 2002; Bendelow, 2009).

The participants' identification with death, HIV and sickness appears to result in their experiencing the self as bad and dangerous. For Nicky and Sihle, this sense of self appeared to be based on their HIV-positive status and internalisation of HIV-related stigma (Ivey, 1990; St. Clair, 2000). Thus, Nicky and Siphso described acquiring Rohleder and Gibson's (2006) spoiled identity. In contrast, Siphso's sense of self as bad appeared to be connected to the internalisation of his abandonment by his early attachment figures (Ivey, 1990; St. Clair, 2000).

The analysis found that all three participants struggle to whole object relate (Hinshelwood, 1991). This is suggested by their use of splitting (Bateman & Holmes, 1995). In addition, in line with research (Green, 1994), the participants expect to be rejected following their

disclosing their HIV status. Thus, it is possible that the participants cannot conceive of their whole selves as being accepted and loved (Hinshelwood, 1991) and so have struggled to internalise a sense of themselves as good (Ivey, 1990; Thomas, 1996). This suggests that the participants experience themselves as part objects (Ivey, 1990).

All three participants portrayed an impoverished sense of self. This is consistent with how literature describes the experience of being HIV-positive (Ferrand *et al*, 2010; Li *et al*, 2010; Rohleder & Gibson, 2006). This impoverished self can be seen in the drawings that all three participants did for Interview 1 and is consistent with the participants' identification with death and sense of self as vulnerable and a part object. This sense of self as a part object appears to have resulted in the participants defensively cutting-off their bodies, sexuality, HIV or everything except their HIV (Bateman & Holmes, 1995; Lemma, 2003). The participants' impoverished sense of selves can be understood as stemming from their difficulty at internalising their intimate relationships (Ivey, 1990; Thomas, 1996).

Lastly, the analysis revealed that the participants' experiences of intimacy and self shaped their experience and perception of sex and sexuality. All three participants experienced sex as bad and dangerous (Deacon *et al*, 2009; Hayes, 2012). This related to sex's connection with HIV-infection. The participants narrated concerns about potentially infecting others (Green, 1994; Kelly *et al*, 2008; Rohleder & Gibson, 2006) and with re-infecting themselves. The latter possibly reflects an internalisation of HIV-related stigma (Deacon *et al*, 2009) and a splitting-off of the anxiety associated with possibly infecting an other (Bateman & Holmes, 1995; Ivey, 1990; Segal, 1992).

However, despite the participants' perception of sex, all three expressed sexual desire, an acknowledgement of others' desire, a desire for an intimate partner and a desire to have children. In this sense the participants conformed to the typical societal discourse regarding sex and sexuality (Bogaert, 2012; Freud, 1905; Hayes, 2012). This can be understood as coming out of the participants' most fundamental need being for connection with others (Epstein, 1991; Ivey, 1990; Lemma, 2003). However, this was complicated for the participants by their HIV status and experience of intimacy and self.

The participants' desire for an intimate partner appeared to be psychologically unattainable. In addition to intimacy being too dangerous for either the self or the other, none of

participants seemed to perceive their whole selves as lovable. Therefore, either the participants do not share their whole selves with the other, and so do not achieve real intimacy, or the participants are rejected for their HIV status. This concern with rejection has been documented in the literature (Green, 1994).

The participants described not wanting to have sexual desire and narrated an ambivalence related to sex and sexuality. The participants described the complexity of sexuality (Burman, 2008; Epstein, 1991; Hayes, 2012; Morgan, 2012; Worthington *et al*, 2002) and the internalisation of the idea that sex says something about a person's sense of self (Deacon *et al*, 2009; Hayes, 2012). In addition, sex was complicated for the participants by heteronormativity (Mohr, 2002; Worthington *et al*, 2002) and constructs of hegemonic masculinity (Jewkes, 2009; Lindegger & Quayle, 2009).

The participants struggled to conceive of sex and sexuality as a whole object (Hinshelwood, 1991). The threat of sex appeared to create persecutory anxieties in the participants (Bateman & Holmes, 1995; Hinshelwood, 1991). This is consistent with the finding that the participants' concern with sex additionally lies in its threat to boundaries (Hayes, 2012). This is external, physical boundaries, emotional boundaries and boundaries of phantasy (Ivey, 1990; Lemma, 2003). Sex appears to elicit concerns of being engulfed and annihilated by the other (Bateman & Holmes, 1995; Lemma, 2003). The most extreme example of this was that all three participants intimately connected sex with rape, abuse and sexual harassment.

The participants appeared to make sex safer by implementing physical and symbolic boundaries that make sex safer in phantasy and external reality (Abraham, 2007; Ivey, 1990; Lemma, 2003; Winnicott, 1971). These boundaries took the form of condoms, having rules about relationships, not disclosing their HIV status prior to sex and cutting themselves off from sexuality.

Ultimately, the analysis revealed that participants' experience of intimacy impacted negatively on their sense of self and therefore on their experience of sex and sexuality. It was consistently found that all three participants experience persecutory anxieties of annihilation. As such it is argued that the lived experience of these vertically-infected HIV-positive adolescents is extremely anxiety provoking.

## 6.2 Value of the research

There are an estimated 33.4 million people globally living with HIV (UNAIDS, 2012c) and of those 3.3 million are children (UNAIDS, 2012b). Across the world, between 2001 and 2006 just over half a million children were vertically-infected per year (UNAIDS, 2012b). This number has decreased each year since 2007, however there were still 330 000 children vertically-infected in 2011 (UNAIDS, 2012b). Sub-Saharan Africa carries most of the HIV-disease burden by accounting for 3.1 million of the globally infected children and 300 000 of the newly vertically-infected children from 2011 (UNAIDS, 2012b). In addition, Southern Africa accounts for one-third of the global HIV-positive population (Halperin & Epstein, 2007) with South Africa having the highest HIV-positive population in the world (UNAIDS, 2012e).

Vertically-infected HIV-positive adolescents represent a significant, and growing, demographic within the HIV pandemic (Ferrand *et al*, 2010). This is especially the case in South Africa given the government's denialism in the late 1990s and early 2000s (Richey, 2008). This denialism resulted in an estimated 35 000 babies unnecessarily being vertically-infected with HIV in South Africa from 2000 to 2005 (Chigwedere *et al*, 2008). South Africa has since vastly improved its treatment of HIV, although 25% of South Africa's HIV-positive mothers are still not receiving PMTCT medication (UNAIDS, 2012d). In addition, the availability of ARVs is now ensuring that an increasing number of these children are surviving into adolescence (Li *et al*, 2010). Therefore, the vertically-infected HIV-positive population will continue to remain a significant demographic.

There is, however, very little research, interventions and support for this demographic (Fernet *et al*, 2007; Ferrand *et al*, 2010; Li *et al*, 2010; Mavedzenge *et al*, 2011). This is detrimental to the lived experience of being a vertically-infected HIV-positive adolescent. In addition, research shows that psychosocial factors impact on safe sex practices and drug adherence (Kelly *et al*, 2008) and so the lack of psychosocial support for this demographic is detrimental in terms of efforts to control the pandemic.

Therefore, this research is valuable because it represents one of the first attempts to understand the in-depth lived experience of being a vertically-infected HIV-positive

adolescent, which in turn can guide further research, intervention and support for this demographic.

In addition to this research's contribution to the academic knowledge concerning vertically-infected HIV-positive adolescents, the research process also appeared to be useful to the research participants themselves. This is because all three participants stated they had found it helpful to talk about themselves, sex and sexuality. Siphso especially found it helpful as the research process enabled him to realise that he does not have to be alone with his HIV status.

### 6.3 Limitations of the research

The findings of this research are limited though for a number of reasons. Firstly, the sample consisted of only three participants and therefore the findings are not representative or generalizable of all vertically-infected HIV-positive adolescents. The findings of this research are only able to represent the experiences of these three research participants. It is therefore the responsibility of those using this research to ensure that it is applicable within their context.

Secondly, the psychoanalytic research interview and qualitative research generally is open to more subjective bias than other methods of research. Therefore, despite this researcher trying to be as critical, reflective and objective as possible, it is probable that the interviews were influenced by some personal bias. In addition, the participants may have been influenced by the demographics of this research as a white, English speaking female and the translator as a black, isiXhosa speaking female. The participants may also have been influenced by the presence of the video-recording camera.

Thirdly, the process of analysis was extremely complex and dense. As a result, it is probable that the analysis failed to identify important nuances in the interviews. In addition, by virtue of the analysis being qualitative, it is possible that it was influenced by some personal bias. However, this was counteracted by critically reflecting on the analysis with the research supervisor.

Lastly, people revert to experiencing persecutory anxieties in times of stress, for example when engaging with their HIV statuses (Segal, 1992; Smiley, 2004). Therefore, while the

analysis found that all three participants experience persecutory anxieties, it is possible that the interviews elicited more persecutory anxiety in the participants than the participants usually experience. Thus, the participants' persecutory anxiety may be isolated to their HIV statuses.

#### 6.4 Recommendations

This research ultimately found that it is extremely challenging to be a vertically-infected HIV-positive adolescent. Therefore, the primary recommendation coming out of this research is that vastly more support and intervention programmes need be provided for this demographic, particularly with regards to the participants' perceptions and understandings of sex and sexuality. It would also be beneficial to provide parents and caregivers of vertically-infected adolescents with more psychosocial support for parenting these adolescents.

However, vastly more research is needed within not only vertically-infected adolescents but also vertically-infected children in order to adequately provide these support and intervention programmes. It is recommended, therefore, that more research be done concerning the lived experience of being a vertically-infected HIV-positive adolescent. It is recommended that this research be especially focused on assessing the effectiveness of different pilot interventions and support groups and generating generalizable results for this demographic.

## 7. Reference List

- Abraham, J. (2007). *The language of Winnicott: A dictionary of Winnicott's use of words* (2<sup>nd</sup> ed.). London, England: Karnac Books.
- Aitken, S. C. (2001). *Geographies of young people: The morally contested spaces of identity*. London, England: Routledge.
- Andersen, S. M., & Przybylinski, E. (2012). Experiments on transference in interpersonal relations: Implications for treatment. *Psychotherapy, 49*(3), 370-383. doi: 10.1037/a0029116
- Ankomah, A., & Ford, N. (1994). Sexual exchange: Understanding pre-marital heterosexual relationships in urban Uganda. In P. Aggleton, P. Davies, & G. Hart (Eds.), *AIDS: Foundations for the future* (pp. 123-135). London, England: Taylor & Francis.
- Auslander, B. A., Rosenthal, S. L., & Blythe, M. J. (2006). Sexual development and behaviours of adolescents. *Psychiatric Annals, 36*(10), 694-702.
- Avert. (2012). *HIV and AIDS in South Africa*. Retrieved from <http://www.avert.org/aidssouthafrica.htm>
- Babbie, E., & Mouton, J. (2005). Qualitative studies. In E. Babbie & J. Mouton (Eds.), *The practice of social research* (pp. 269-311). Cape Town, South Africa: Oxford University Press.
- Bardhan, N. R. (2002). Accounts from the field: A public relations perspective on global AIDS/HIV. *Journal of Health Communication, 7*, 221 – 244. doi: 10.1080/10810730290088102
- Bateman, A., & Holmes, J. (1995). *Introduction to psychoanalysis: Contemporary theory and practice*. London, England: Routledge.
- Bendelow, G. (2009). *Health, emotion and the body*. Cambridge, England: Polity Press.
- Bogaert, A. F. (2012). *Understanding asexuality*. Lanham, Maryland: Rowan & Littlefield Publishers.
- Brinich, P., & Shelley, C. (2002). *The self and personality structure*. Buckingham, England: Open University Press.
- Brown, D. C., BeLue, R., & Airhihenbuwa, C. O. (2010). HIV and AIDS-related stigma in the context of family support and race in South Africa. *Ethnicity & Health, 15*(5, October), 441-458.
- Bukatko, D., & Daehler, M. W. (2004). *Child development: A thematic approach*. Boston, MA: Houghton Mifflin Company.

- Burman, E. (2008). *Developments: Child, image, nation*. East Sussex, England: Routledge.
- Burrow, A. L., & Hill, P. L. (2011). Purpose as a form of identity capital for purposive youth adjustment. *Developmental Psychology*, 47(4), 1198-1206. doi:10.1037/a0023818
- Camic, P. M., Rhodes, J. E., & Yardley, L. (2003). Naming the stars: Integrating qualitative methods into psychological research. In P. M. Camic, J. E. Rhodes, & L. Yardley (Eds.), *Qualitative research in psychology: Expanding perspective in methodology and design* (pp. 3–15). Washington, DC: American Psychological Association.
- Cartwright, D. (2004). The psychoanalytic research interview: Preliminary suggestions. *Journal of the American Psychoanalytic Association*, March(24), 209-22.
- Chigwedere, P., Seage, G. R., Guskin, S., Lee, T., & Essex, M. (2008). Estimating the lost benefits of antiretroviral drug use in South Africa. *J Acquir Immune Defic Syndr*, 00(0), 1-6.
- Copley, B. (1993). *The world of adolescence: Literature, society and psychoanalytic psychotherapy*. London, England: Free Association Books.
- Cornwall, A., Corrêa, S., & Jolly, S. (2008). Development with a body: Making the connections between sexuality, human rights and development. In A. Cornwall, S. Corrêa, & S. Jolly (Eds.), *Development with a body: Sexuality, human rights, and development* (pp. 1-21). London, England: Zed Books.
- Cox, M. V., & Catte, M. (2000). Severely disturbed children's human figure drawings: Are they unusual or just poor drawings? *European Child & Adolescent Psychiatry*, 9, 301-306.
- Cozby, P. C. (2005). *Methods in behavioural research*. New York: McGraw-Hill.
- Deacon, H., Uys, L., & Mohlahlane, R. (2009). HIV and stigma in South Africa. In P. Rohleder, L. Swartz, S. C. Kalichman, & L. C. Simbayi (Eds.), *HIV/AIDS in South Africa 25 Years On* (pp. 123-134). New York, NY: Springer.
- Denscombe, M. (2010). *The good research guide for small-scale social research projects* (4<sup>th</sup> ed.). Berkshire, England: Open University Press.
- DiLeo, J. H. (1973). *Children's drawings as diagnostic aids*. New York: Bruner/Mazel.
- DiLeo, J. H. (1983). *Interpreting children's drawings*. New York: Bruner/Mazel.
- Durrheim, K. (1999). Research design. In M. Terre Blanche & K. Durrheim (Eds.), *Research in practice* (pp. 29 – 53). Cape Town: UCT Press.
- Durrheim, K., & Painter, D. (2006). Collecting quantitative data: Sampling and measuring. In M. Terre Blanche, K. Durrheim, & D. Painter (Eds.), *Research in practice: Applied*

- methods for the social science* (2<sup>nd</sup> ed.) (pp. 131 – 159). Cape Town: University of Cape Town Press.
- Ebersöhn, L., & Eloff, I. (2002). The black, white and grey of rainbow children coping with HIV/AIDS. *Perspectives in Education*, 20(2), 77-86.
- Eliason, M. J. (1995). Accounts of sexual identity formation in heterosexual students. *Sex Roles*, 32(11/12), 821-834.
- Emanuel, E. J., Wendler, D., & Grady, C. (2000). What makes clinical research ethical? *The Journal of the American Medical Association*, 283(20), 2701-2711.
- Epstein, S. (1991). Sexuality and identity: The contribution of object relations theory to a constructionist sociology. *Theory and Society*, 20, 825-873.
- Erikson, E. H. (1950). *Childhood and society*. London, England: Imago Publishing.
- Fernet, M., Proulx-Boucher, K., Richard, M., Lévy, J. J., Otis, J., Samson, J., Massie, L., Lapointe, N., Thériault, J., & Trottier, G. (2007). Issues of sexuality and prevention among adolescents living with HIV/AIDS since birth. *The Canadian Journal of Human Sexuality*, 16(3-4), 101-111.
- Ferrand, R., Lowe, S., Whande, B., Munaiwa, L., Langhaug, L., Cowan, F., Mugurungi, O., Gibb, D., Munyati, S., Williams, B. G., & Corbett, E. L. (2010). Survey of children accessing HIV services in a high prevalence setting: Time for adolescents to count? *Bull World Health Organ*, 88, 428-434. doi:10.2471/BLT.09.066126
- Freud, S. (1905). Three essays on the theory of sexuality. In J. Strachey, A. Freud, A. Strachey, & A. Tyson (Eds.), *The standard edition of the complete psychological works of Sigmund Freud: Volume VII (1901 – 1905)* (pp. 135 – 245). London, England: The Hogarth Press and the Institute of Psycho-analysis.
- Green, G. (1994). Positive sex: Sexual relationships following an HIV-positive diagnosis. In P. Aggleton, P. Davies, & G. Hart (Eds.), *AIDS: Foundations for the future* (pp. 136-146). London, England: Taylor & Francis.
- Greenberg, J. R., & Mitchell, S. A. (1983). *Object relations in psychoanalytic theory*. London, England: Harvard University Press.
- Hall, R. (2008). *Applied social research: Planning, designing and conducting real-world research*. South Yarra, Australia: Palgrave Macmillan.
- Halperin, D. T., & Epstein, H. (2007). Why is HIV prevalence so severe in Southern Africa? The role of multiple concurrent partnerships and lack of male circumcision: Implications for AIDS prevention. *The South African Journal of HIV Medicine*, March, 19-25.

- Hayes, G. (2012). Desire in the time of AIDS. In A. Gulerce (Ed.), *Re(con)figuring psychoanalysis: Critical juxtapositions of the philosophical, the sociohistorical and the political* (pp. 146-163). Basingstoke, England: Palgrave Macmillan.
- Health and Development Africa. (2012). *Global HIV response progress report 2012: Republic of South Africa*. Retrieved from [http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2012countries/ce\\_ZA\\_Narrative\\_Report.pdf](http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2012countries/ce_ZA_Narrative_Report.pdf)
- Herbert, M. (1998). *Clinical child psychology: Social learning, development and behaviour* (2<sup>nd</sup> ed.). Chichester, England: John Wiley & Sons.
- Hinshelwood, R. D. (1991). *A dictionary of Kleinian thought*. London, England: Free Association Books.
- Hinshelwood, R. D. (1994). *Clinical Klein: From theory to practice*. London, England: BasicBooks.
- Holder-Perkins, V., & Akman, J. S. (2006). Psychological reactions. In F. Fernandez, & P. Ruiz (Eds.), *Psychiatric aspects of HIV/AIDS* (pp. 71-79). Philadelphia, PA: Lippincott Williams & Wilkins.
- Hollway, W., & Jefferson, T. (2000). *Doing qualitative research differently: Free association, narrative and the interview method*. London, England: Sage Publications.
- Ivey, G. (1990). *An introduction to object relations theory*. Unpublished manuscript.
- Jervis, S. (2011). *Relocation, gender, and emotions: A psycho-social perspective on the experiences of military wives*. London, England: Karnac Books.
- Jewkes, R. (2009). HIV and women. In P. Rohleder, L. Swartz, S. C. Kalichman, & L. C. Simbayi (Eds.), *HIV/AIDS in South Africa 25 years on* (pp. 27-40). New York, NY: Springer.
- Joint United Nations Programme on HIV/AIDS (UNAIDS). (2012a). *Fact sheet*. Retrieved from [http://www.unaids.org/en/media/unaids/contentassets/documents/factsheet/2012/20120417\\_FS\\_adolescentsyoungpeoplehiv\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/factsheet/2012/20120417_FS_adolescentsyoungpeoplehiv_en.pdf)
- Joint United Nations Programme on HIV/AIDS (UNAIDS). (2012b). *Global fact sheet: World AIDS day 2012*. Retrieved from [http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/gr2012/20121120\\_FactSheet\\_Global\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/gr2012/20121120_FactSheet_Global_en.pdf)

- Joint United Nations Programme on HIV/AIDS (UNAIDS). (2012c). *Global report: UNAIDS report on the global AIDS epidemic 2010*. Retrieved from [http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2010/20101123\\_globalreport\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2010/20101123_globalreport_en.pdf)
- Joint United Nations Programme on HIV/AIDS (UNAIDS). (2012d). *Regional fact sheet 2012: Sub-Saharan Africa*. Retrieved from [http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/gr2012/2012\\_FS\\_regional\\_ssa\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/gr2012/2012_FS_regional_ssa_en.pdf)
- Joint United Nations Programme on HIV/AIDS (UNAIDS). (2012e). *UNIADS World AIDS Day Report: Results 2012*. Retrieved from [http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/gr2012/JC2434\\_WorldAIDSday\\_results\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/gr2012/JC2434_WorldAIDSday_results_en.pdf)
- Kang, E., Mellins, C. A., Yiu Kee Ng, W., Robinson, L., & Abrams, E. J. (2008). Standing between two worlds in Harlem: A developmental psychopathology perspective of perinatally acquired human immunodeficiency virus and adolescence. *Journal of Applied Developmental Psychology, 29*, 227-237. doi: 10.1016/j.appdev.2008.02.0001
- Kelly, K., Freeman, M., Nkomo, N., & Ntlabati, P. (2008). The vicious circularity of mental health effects of HIV/AIDS: Symptom and cause of poor responses to the epidemic. In V. Moller, & D. Huschka (Eds.), *Quality of life and the millennium challenge* (pp. 223-237). Dordrecht, Netherlands: Springer.
- King, N., & Horrocks, C. (2010). *Interviews in qualitative research*. London, England: Sage Publications.
- Klein, M. (1932). *The psych-analysis of children*. London, England: Leonard & Virginia Woolf and the Institute of Psycho-analysis.
- Klein, M. (1952). The origins of transference. In D. E. Scharff (Ed.), *Object relations theory and practice: An introduction* (pp. 156 – 160). London, England: Jason Aronson.
- Knoff, H. M., & Prout, H. T. (1985). *Kinetic drawing system for family and school: A handbook*. Los Angeles: Western Psychological Services.
- Kruegar, R. A., & Casey, M. A. (2000). *Focus groups (3<sup>rd</sup> ed.): A practical guide for applied research*. Thousand Oaks, CA: Sage Publications.
- Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing*. Thousand Oaks, CA: Sage Publications.
- Long, C. (2009). *Contradicting maternity: HIV-positive motherhood in South Africa*. Johannesburg, South Africa: Wits University Press.

- Lemma, A. (2003). *Introduction to the practice of psychoanalytic psychotherapy*. Chichester, England: John Wiley & Sons.
- Lesch, A., Swartz, L., Kagee, A., Moodley, K., Kafaar, Z., Myer, L., & Cotton, M. (2007). Paediatric HIV/AIDS disclosure: towards a development and process oriented approach. *AIDS Care*, *19*(6), 811-816. doi:10.1080/0954020601129301
- Li, R. J., Jaspan, H. B., O'Brien, V. O., Rabie, H., Cotton, M. F., & Nattrass, N. (2010). Positive features: A qualitative study on the needs of adolescents on antiretrovirals therapy in South Africa. *Aids Care*, *22*(6), 751-758. doi:10.1080/09540120903431363
- Liddicoat, A. J. (2011). *An introduction to conversation analysis*. London, England: Continuum International Publishing Group.
- Likierman, M., & Urban, E. (1999). The roots of child and adolescent psychotherapy in psychoanalysis. In M. Lanyado, & A. Horne (Eds.), *The handbook of child and adolescent psychotherapy* (pp. 19–30). East Sussex, England: Routledge.
- Lindegger, G., & Quayle, M. (2009). Masculinity and HIV/AIDS. In P. Rohleder, L. Swartz, S. C. Kalichman, & L. C. Simbayi (Eds.), *HIV/AIDS in South Africa 25 years on* (pp. 41-54). New York, NY: Springer.
- MacGregor, H. N. (2009). Mapping the body: Tracing the personal and the political dimensions of HIV/AIDS in Khayelitsha, South Africa. *Anthropology & Medicine*, *16*(1, April), 85-95.
- Malan, D. H. (1979). *Individual psychotherapy and the science of psychodynamics*. London, England: Butterworths.
- Mavedzenge, S. N., Olson, R., Doyle, A. M., Phil, M., Changanalucha, J., & Ross, D. A. (2011). The epidemiology of HIV among young people in Sub-Saharan Africa: Know your local epidemic and its implications for prevention. *Journal of Adolescent Health*, *49*, 559-567. doi:10.1016.j.jadohealth.2011.02.012
- Mohr, J. J. (2002). Heterosexual identity and the heterosexual therapist: An identity perspective on sexual orientation dynamics in psychotherapy. *The Counselling Psychologist*, *30*(4, July), 532-566. doi: 10.1177/00100002030004003
- Morgan, E. M. (2012). Not always a straight path: College students' narratives of heterosexual identity development. *Sex Roles*, *66*, 79-93. doi:10.1007/s11199-011-0068-4
- Mortensen, K. V. (1991). *Form and content in children's human figure drawings: Development, sex differences, and body experience*. New York, NY: New York University Press.

- Nuttall, J. (1998). Fairbairnian object relations: The challenge to the moral defence in gay men with HIV. *Psychodynamic Counselling*, 4(4), 445-461.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods*. Thousand Oaks, CA: Sage Publications.
- Piko, B., & Bak, J. (2006). Children's perceptions of health and illness: Images and lay concepts in preadolescence. *Health Educational Research: Theory and Practice*, 21(5), 643-653.
- Richey, L. A. (2008). Science, denial and politics: "Boundary work" in the provision of AIDS treatment in South Africa. *New Political Science*, 30(1, March), 1-21.  
Doi:10.1080/07393140701871216
- Rohleder, P., & Gibson, K. (2006). 'We are not fresh': HIV-positive women talk of their experience of living with their 'spoiled identity'. *South African Journal of Psychology*, 36(1), 25 – 44.
- Sayre, G., & Halling, S. (2007). When more is better: Dialoging with video data. *The Humanistic Psychologist*, 36(4), 387-399.
- Segal, J. (1992). *Melanie Klein*. London, England: Sage Publications.
- Shaw, R. (2010). QM3: Interpretative phenomenological analysis. In M. A. Forrester (Ed.), *Doing qualitative research in psychology: A practical guide* (pp. 177-201). London, England: Sage Publications.
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London, England: Sage Publications.
- Smith, J. A., & Osborn, M. (2008). Interpretative Phenomenological Analysis. In G. M. Breakwell (Ed.), *Doing social psychology research* (pp. 53-80). Oxford, England: The British Psychology Society and Blackwell Publishing.
- Smiley, A. (2004). The intrapsychic realm of HIV/AIDS and related homelessness: Two case studies. *Clinical Social Work Journal*, 32(3), 251-269.
- South African Department of Health. (2011). *National Health Act (Act 61 of 2003): Policy on National Health Insurance* (Government Notice No. 657). Retrieved from [http://us-cdn.creamermedia.co.za/assets/articles/attachments/34471\\_nhi.pdf](http://us-cdn.creamermedia.co.za/assets/articles/attachments/34471_nhi.pdf)
- St. Clair, M. (2000). *Object relations and self psychology: An introduction* (3<sup>rd</sup> ed.). Scarborough, Canada: Wadsworth.
- Striepe, M. I., & Tolman, D. T. (2003). Mom, Dad, I'm straight: The coming out of gender ideologies in adolescent sexual-identity development. *Journal of Clinical Child and Adolescent Psychology*, 32(4), 523-530.

- Tang, G. (2010). *A case study of South Africa's PMTCT policy before and after the treatment action campaign social movement*. Retrieved from <http://king.bol.ucla.edu/conference/tang.pdf>
- Taylor, S. J., & Bogdan, R. (1984). *Introduction to qualitative research methods: The search for meaning* (2<sup>nd</sup> ed.). New York, NY: John Wiley & Sons.
- Thomas, K. (1996). The defensive self: A psychodynamic perspective. In R. Stevens (Ed.), *Understanding the self* (pp. 281-338). London, England: Sage Publications.
- United Nations Children's Fund (UNICEF). (2011). *Opportunity in crisis: Preventing HIV from early adolescence to young adulthood*. Retrieved from [http://www.unicef.org/media/files/Opportunity\\_in\\_Crisis\\_LoRes\\_EN\\_05182011.pdf](http://www.unicef.org/media/files/Opportunity_in_Crisis_LoRes_EN_05182011.pdf)
- Van der Riet, M., & Durrheim, K. (2006). Putting design into practice: Writing and evaluating research proposals. In M. Terre Blanche, K. Durrheim, & D. Painter (Eds.), *Research in practice: Applied methods for the social science* (2<sup>nd</sup> ed.) (pp. 80 – 111). Cape Town: University of Cape Town Press.
- Wachsler-Felder, J. L., & Golden, C. J. (2002). Neuropsychological consequences of HIV in children: A review of current literature. *Clinical Psychology Review*, 22, 441-462.
- Winnicott, D. W. (1971). *Playing and reality*. London, England: Tavistock Publications.
- Worthington, R. L., Savoy, H. B., Dillon, F. R., & Vernaglia, E. R. (2002). Heterosexual identity development: A multidimensional model of individual and social identity. *The Counselling Psychologist*, 30(4, July), 496-531.  
doi:10.1177/00100002030004002
- Yarhouse, M. A., & Tan, E. S. N. (2004). *Sexual identity synthesis: Attributions, meaning-making, and the search for congruence*. Lanham, Maryland: University Press of America.

## **Appendix A: Letter of request to the Raphael Centre**

Dear Ms. van Niekerk

My name is Lindsay Smaill, and I am currently registered for my Masters in Counselling Psychology at Rhodes University. As part of my degree I am required to undertake a research project. The focus of my research is to deeply understand how vertically-infected HIV-positive adolescents experience intimacy, sex and sexuality in relation to their HIV status. I would hereby like to request permission to be able to conduct my research through the Raphael Centre, as the gatekeepers of potential participants.

Adolescence is complicated for vertically-infected HIV-positive adolescents because of the impact that their HIV status has on intimacy, sex and sexuality. The purpose of the research is therefore to deeply explore how vertically-infected HIV-positive adolescents integrate their lived social and interpersonal experiences intrapsychically. There is extremely limited research concerning vertically-infected HIV-positive adolescents and so it is hoped that this research project would provide the beginnings of the most basic and fundamental exploratory knowledge towards a subjective understanding of these adolescents.

My intention is to have three participants with whom I will conduct two, one and a half hour, in-depth semi-structured individual interviews. Each interview will be structured around a projective drawing that the participants will do during the interview: a drawing of their body map and a drawing of what they conceive sexuality to look like. Interview themes or questions will focus around what their different identities of being HIV-positive, an adolescent, and having an emerging sexuality mean to them; what sexuality means to them; and barriers and facilitators to sexuality and intimacy. These interviews will be done at Rhodes University, at a time that is convenient for each participant. My supervisor, Ms. Ruby Patel, who is a registered psychologist, may watch the interviews through one-way glass to provide additional support. With participants' permission the interviews will be videotaped in order to understand as accurately and as fully as possible what they may say in the interviews. Everything from the interviews will be kept confidential. The videotapes will be destroyed as soon as they have been transcribed and the relevant information documented. Identifying information will also be destroyed. Only the transcripts and drawings, without any identifying information, will be kept as the property of Rhodes University for possible future research. No identifying information will be included in the research report.

Once the research report is complete a copy of it will be given to you, the Raphael Centre, with the understanding that you will not share the report with anyone who may know participants well enough so as to be able to identify them from the report. In addition I will give some general, so as not to reveal exactly which participant disclosed what, feedback to participants and their parents or guardians.

In the event of psychological distress occurring as a result of participation in this study, participants you will be referred to a psychologist at the Rhodes Psychology Clinic. However, I am a training psychologist, and my supervisor is practicing psychologist, and so we expect to be able to contain any distress that participants may experience during the interviews.

I include herewith my research proposal for further information. Either my supervisor or I can be reached at the numbers provided below for any further questions.

Thank you.

Yours Sincerely

Lindsay Smail

Principal Researcher

Tel: 072 538 0440 or 046 603 7417

E-mail: lasmaill@gmail.com

Supervisor: Ms. Ruby Patel.

Tel: 082 045 0620 or 046 603 8816

E-mail: r.patel@ru.ac.za

## Appendix B: Permission from the Raphael Centre

	<b>Raphael Centre</b> Voluntary Counselling and HIV Testing NPO number: 072-238-NPO	11 Donkin Street <b>Grahamstown</b> 6139 <b>South Africa</b> e-mail: <a href="mailto:avanniekerk@albanynet.co.za">avanniekerk@albanynet.co.za</a> phone & fax: +27 (0)46 622 8831
---	---	---

To whom it may concern

This letter is to confirm that we, the Raphael Centre, have given permission for Lindsay Smail to conduct her research for the completion of her Master's Degree through us. We will approach participants who are part of our "adolescents who are affected by HIV" youth group who we know meet her research requirements and might be interested in participating. If they are open to the idea we will facilitate a meeting between them, their parents or guardians, and Lindsay. At this meeting we will facilitate an explanation of what the research is about, what the research would require of the participant, and the process of consent. In addition, if required, we will also provide a translator, who will be financed by Lindsay.

We are willing to do this provided that: the research proposal is passed by the Rhodes ethics board, that we will be acknowledged in the research report, and that we will have access to the completed research report.

We are in full support of the research proposed by Lindsay. When she first approached us with the idea of doing research with HIV-positive children she asked if there was anything that we would particularly like researched and we immediately identified the sexuality of vertically-infected HIV-positive adolescents. This is because we are finding that there are firstly increasing numbers of vertically-infected adolescents, and secondly that these adolescents keep approaching us for help with regard to their sexuality. Therefore, this research would be extremely useful for us.

Lastly, we have worked with Lindsay in the past when she volunteered with us during her Undergraduate Degree. We know that she is a unique, motivated, and committed individual who we trust to conduct this research with the required sensitivity.

Yours sincerely

Jubu van Niekerk



**RHODES UNIVERSITY**  
*Where leaders learn*

Rhodes University Ethical Standards Committee, Rhodes University, P O Box 94, Grahamstown, 6140  
Tel: +27 46 603 7366 • Fax: +27 46 603 8934 • email: [M.Goebel@ru.ac.za](mailto:M.Goebel@ru.ac.za)

21 Aug 2012

Dear Ms Smaill,

**Ethics Clearance: 2012Q3-6**  
**Principal Investigators: Lindsay Smaill**

This letter confirms that the research proposal with tracking numbers 2012Q3-6 “Sexuality, intimacy and identity: The experiences of vertically-infected HIV positive adolescents” was given ethics clearance by the Rhodes University Ethical Standards Committee.

Please ensure that the ethical standards committee is notified should any substantive change(s) be made, for whatever reason, during the research process. This includes changes in investigators. Please also ensure that a brief report is submitted to the ethics committee on completion of the research. The purpose of this report is to indicate whether or not the research was conducted successfully, if any aspects could not be completed, or if any problems arose that the ethical standards committee should be aware of. If a thesis or dissertation arising from this research is submitted to the library’s electronic theses and dissertations (ETD) repository, please notify the committee of the date of submission and/or any reference or cataloguing number allocated.

Yours sincerely

Professor M. Göbel: Chairperson RUEESC.

**Note:**

1. This clearance is valid from the date on this letter to the time of completion of data collection.
2. The ethics committee cannot grant retrospective ethics clearance.
3. Progress reports should be submitted annually unless otherwise specified in the clearance letter.

## **Appendix D: Participant Information Sheet**

My name is Lindsay Smaill, and I am doing research as part of my Masters in Counselling Psychology at Rhodes University. The focus of my research is to understand how HIV-positive adolescents who have been positive since birth experience being a teenager. It will focus specifically on how they experience intimacy, sex and sexuality. It is hoped that this research will produce the most basic and fundamental knowledge towards understanding vertically-infected HIV-positive adolescents.

I would like to invite you to participate in this study. Participation will involve being interviewed twice by me, at Rhodes University, at a time that is convenient for you. My supervisor, Ms. Ruby Patel, who is a registered psychologist, may watch our interviews through one-way glass. You will be interviewed for about one and a half hours per interview. Each interview will involve you drawing a picture of your experience as an HIV-positive adolescent who is starting to think about sex, and us talking about it. You may refuse to answer any questions you would prefer not to, and you may choose to withdraw from the study at any point without any negative consequences.

With your permission the interview will be videotaped in order to understand as accurately and fully as possible what you say. Participation is voluntary, and no person will be advantaged or disadvantaged in any way for choosing to participate or not to participate in the study. Everything you communicate in the interviews will be kept confidential, and no information that could identify you would be included in the research report. The interview material (videotapes, transcripts, and drawings) will not be seen or heard by any person other than myself and my supervisor. Whilst I am working on transcribing the videotapes, they will be kept in a locked cabinet at my office with my other clinical material to ensure confidentiality. Once the transcripts are complete, and the relevant information from the videotapes documented, the videotapes and any identifying information will be destroyed. Only the transcripts and drawings, without any identifying information, will be kept as the property of Rhodes University for possible future research.

In the event of psychological distress occurring as a result of participation in this study, you will be referred to a psychologist at the Rhodes Psychology Clinic. However, I am a training psychologist, and my supervisor is qualified psychologist, and so we expect to be able to contain any distress that you may experience during the interviews.

Once the research report is complete a copy of it will be given to the Director of the Raphael Centre, who highly values your confidentiality and so will not share the report with anyone who may know you well enough to be able to identify you even without your identifying information being present. In addition I will give some general, so as not to reveal exactly which participant disclosed what, feedback to you and your parents or guardians.

In taking part in this research I hope to be able to provide people, and appropriate health care professionals and organisations, with a basic, deep understanding of what it is like to be a vertically-infected HIV-positive adolescent.

If you have any questions I can be contacted at the Rhodes Psychology Clinic on 046 603 7417.

## **Appendix E: Guardian consent form**

### **Rhodes University: Department of Psychology** **Agreement between student researcher and parent or guardian**

I \_\_\_\_\_ affirm that I am the legal guardian of \_\_\_\_\_. I grant permission for my child to participate in the research project of Lindsay Smaill on how vertically-infected HIV-positive adolescents experience intimacy, sex and sexuality.

#### **I understand that:**

1. The researcher is a student conducting research as part of the requirement for a Master of Arts Degree in Counselling Psychology at Rhodes University. The researcher may be contacted on 046 603 7417 or l.smaill@ru.ac.za. The research project has been approved by the relevant ethics committee. It is under the supervision of Ms. Ruby Patel, a registered psychologist in the Psychology Department at Rhodes University, who may be contacted on 046 603 8816 or r.patel@ru.ac.za.
2. The researcher is interested in how vertically-infected HIV-positive adolescents experience intimacy, sex and sexuality in relation to their HIV status.
3. My child's participation will involve two, one and a half hour, in-depth individual interviews structured around a drawing of their experience as vertically-infected HIV-positive adolescents that they will do during the interview. The interview will involve discussion about what their different identities of being HIV-positive, an adolescent, and having an emerging sexuality mean to them; and barriers and facilitators to sexuality and intimacy.
4. The research supervisor, Ms. Ruby Patel, may watch the interviews through one-way glass to provide additional support. The interviews will be video recorded, but these will be destroyed once they have been transcribed and the relevant visual data documented.
5. My child will be asked questions of a personal nature, but he/she can choose not to answer any questions about aspects of their lives which they are not willing to disclose.
6. I am invited to voice to the researcher any concerns I have about my child's participation, and to have these addressed to my satisfaction. The Rhodes Psychology Clinic may be contacted on 046 603 8502 for counselling should I feel that my child is distressed, embarrassed, or offended as a result of participating.
7. My child is free to withdraw from the study at any time – however I commit my child to full participation unless some unusual circumstances occur, or I have concerns about my child's participation which I did not originally anticipate.
8. The report on this project will contain information about my child's personal experiences, attitudes, and behaviours, but the report will be designed in such a way that my child's identity cannot be identified by the general reader. The Director of the Raphael Centre will receive the research report but will not share the report with anyone who may know my child well enough to be able to identify them.

Signed on:

Parent: \_\_\_\_\_ Researcher: \_\_\_\_\_

## **Appendix F: Participant ascent form**

### **Rhodes University: Department of Psychology** **Agreement between student researcher and participant minor**

I \_\_\_\_\_ agree to participate in the research project of Lindsay Smaill on how vertically-infect HIV-positive adolescents experience intimacy, sex and sexuality.

#### **I understand that:**

1. The researcher is a student conducting research as part of the requirement for a Master of Arts Degree in Counselling Psychology at Rhodes University. The researcher may be contacted on 046 603 7417 or l.smaill@ru.ac.za. The research project has been approved by the relevant ethics committee. It is under the supervision of Ms. Ruby Patel, a registered psychologist in the Psychology Department at Rhodes University, who may be contacted on 046 603 8816 or r.patel@ru.ac.za.
2. The researcher is interested in how vertically-infected HIV-positive adolescents experience intimacy, sex and sexuality in relation to their HIV status.
3. My participation will involve two, one and a half hour, in-depth individual interviews structured around a drawing that I will do about my experience as a vertically-infected HIV-positive adolescent. The interview will need me to talk about my different identities of being HIV-positive, an adolescent, and having an emerging sexuality; as well as barriers and facilitators to sexuality and intimacy.
4. The research supervisor, Ms. Ruby Patel, may watch the interviews through one-way glass to provide additional support. The interviews will be video recorded, but these will be destroyed once they have been transcribed and the relevant visual data documented.
5. I will be asked questions of a personal nature, but I can choose not to answer any questions about aspects of my life which I am not willing to disclose.
6. I am invited to voice to the researcher any concerns I have about my participation, and to have these addressed to my satisfaction. The Rhodes Psychology Clinic may be contacted on 046 603 8502 for counselling should I feel distressed, embarrassed, or offended as a result of participating.
7. I am free to withdraw from the study at any time – however I commit to full participation unless some unusual circumstances occur, or I have concerns about my participation which I did not originally anticipate.
9. The report on this project will contain information about my personal experiences, attitudes, and behaviours, but the report will be designed in such a way that my identity cannot be identified by the general reader. The Director of the Raphael Centre will receive the research report but will not share the report with anyone who may know me well enough to be able to identify me.

Signed on:

Participant: \_\_\_\_\_ Researcher: \_\_\_\_\_

**USE OF TAPE RECORDINGS FOR RESEARCH  
PURPOSES**

-

**PERMISSION AND RELEASE FORM**

<i>Participant name &amp; contacts (address, phone etc)</i>	
<i>Name of researcher &amp; level of research (Honours/Masters/PhD)</i>	
<i>Brief title of project</i>	
<i>Supervisor</i>	

**Declaration**

*(Please initial/tick blocks next to the relevant statements)*

1. <i>The nature of the research and the nature of my participation have been explained to me</i>	verbally	
	in writing	
2. <i>I agree to be interviewed and to allow tape-recordings to be made of the interviews</i>	audiotape	
	videotape	
3. <i>I agree to take part in and to allow tape-recordings to be made.</i>	audiotape	
	videotape	
4. <i>The tape recordings may be transcribed</i>	without conditions	
	only by the researcher	
	by one or more nominated third parties:	
5.1 <i>I have been informed by the researcher that the tape recordings will be erased once the study is complete and the report has been written.</i>		
5.2 <i>OR I give permission for the tape recordings to be retained after the study and for them to be utilised for the following purposes and under the following conditions:</i>		

**Signatures**

<i>Signature of participant</i>		<i>Date</i>
<i>Witnessed by researcher</i>		

**Appendix H: Agreement with the translator**

**Rhodes University: Department of Psychology**  
**Agreement between student researcher and student translator**

I \_\_\_\_\_ agree to be the translator in the research project of Lindsay Smaill on how vertically-infected HIV-positive adolescents experience intimacy, sex and sexuality.

**I understand that:**

1. The researcher is a student conducting research as part of the requirement for a Master of Arts Degree in Counselling Psychology at Rhodes University. The researcher may be contacted on 046 603 8502 or l.smaill@ru.ac.za. The research project has been approved by the relevant ethics committee. It is under the supervision of Ms. Ruby Patel, a registered psychologist in the Psychology Department at Rhodes University, who may be contacted on 046 603 8816 or r.patel@ru.ac.za.
2. The researcher is interested in how vertically-infected HIV-positive adolescents experience intimacy, sex and sexuality in relation to their HIV status.
3. My participation will involve, at minimum, translating and transcribing two, one and a half hour, in-depth individual interviews structured around a drawing of their experience as vertically-infected HIV-positive adolescents.
4. The interviews will be video recorded, but these will be destroyed once they have been transcribed and the relevant visual data documented.
5. All information concerning the research participants and what happens in the course of the interviews, including the identity of participants, is strictly confidential and may not be spoken about except with the researcher and supervisor.
6. The Rhodes Psychology Clinic may be contacted on 046 603 8502 for counselling should I feel that my participation has left me distressed, embarrassed, or offended.

Signed on:

Translator: \_\_\_\_\_ Researcher: \_\_\_\_\_

Appendix I: Sihle's drawing for Interview 1

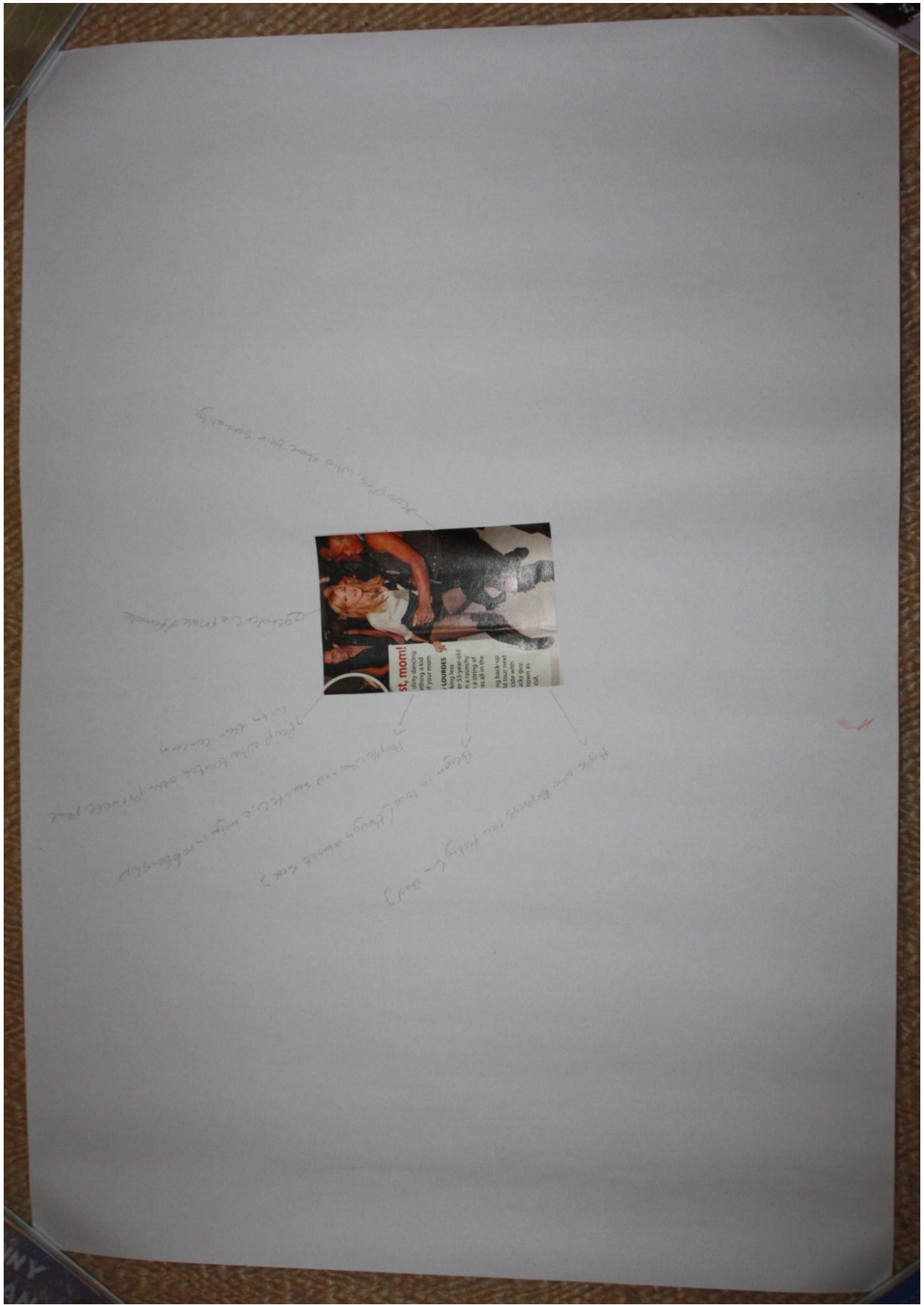


**Appendix J: Sihle's drawing for Interview 2**

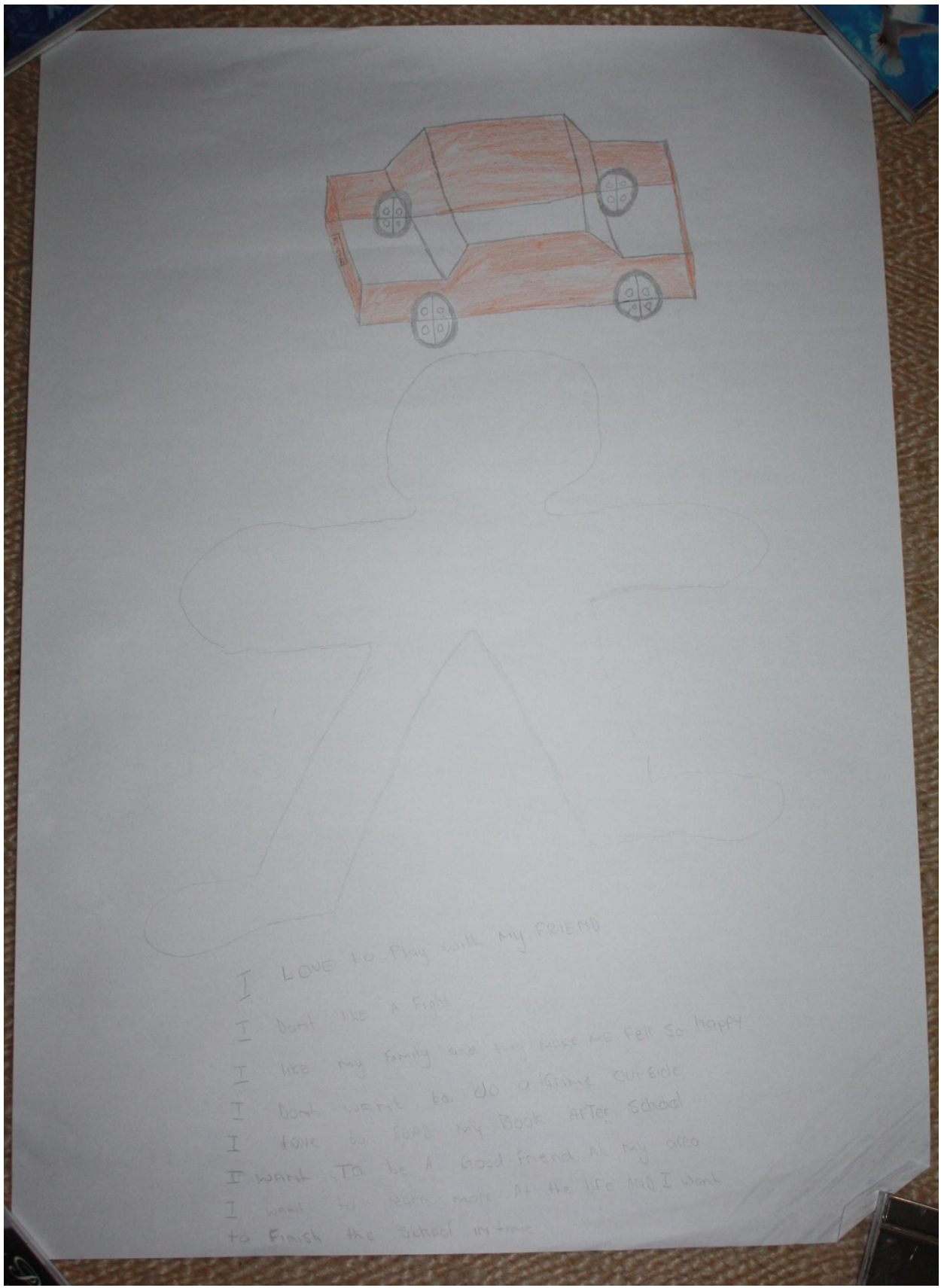




Appendix L: Nicky's drawing for Interview 2



Appendix M: Sipho's drawing for Interview 1



Appendix N: Siphos drawing for Interview 2

