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Antiretroviral treatment adherence in South Africa: An adolescent perspective

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Research Proposal

Master of Arts in Clinical Psychology

University of the Witwatersrand 2011

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A research report submitted in partial fulfillment of the requirements for the degree of M.A. Clinical Psychology by Coursework and Research Report in the field of Psychology, School of Human and Community Development, in the Faculty of Humanities, University of the Witwatersrand, Johannesburg

Declaration

I declare that this thesis is my own original, unaided work. It is submitted in partial fulfillment of the requirements for the degree Master of Arts in Psychology (by Coursework and Research Report) in the Department of Psychology, School of Human and Community Development, University of the Witwatersrand. It has not been submitted for any other degree or examination at any other university or institution.

_____ _____

Candidate: Natasha Maswikiti **Supervisor: Prof. Katherine Bain**

Date…… **Date: ……**

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Abstract

The introduction of Antiretroviral (ARV) treatment has allowed for many children living with human immunodeficiency virus (HIV) to survive to adolescence. However for this to be a reality adherence to treatment is important. Many studies suggest that during adolescence adherence can be very challenging. However not much research has been done within the South African context to understand what HIV positive adolescents are experiencing, particularly in relation to ARV adherence. The aim of this research study was to explore the experiences of adolescents on antiretroviral therapy (ART) in order to understand what helps them to adhere to their medication and the challenges that they may have with adherence. This was achieved by carrying out 5 semi-structured in-depth interviews with HIV positive adolescents on ARVS at a shelter for HIV positive women and children in Johannesburg. A thematic content analysis was used to analyse the transcribed interviews. The results indicated several factors that both assist with adherence and those that challenge adherence. The participants reflected on the importance of full disclosure which increases their understanding of the importance of adherence, having people they trust whom they can confide in and who also support them to take and adhere to the ARVs, and having a positive experience at the hospital when they go for their regular checkups. Certain defence mechanisms adopted by the adolescents to help them cope with living with HIV and having to take medication every single day of their lives were also identified. The fact that acceptance is a process was also suggested by the research findings. The challenges the adolescents face were those of stigma and a fear of being rejected, bad experiences associated with taking medication, such as the negative side effects and the disruption of their leisure time, and negative experiences from going to the hospital. This study yielded some rich information that may aid in understanding what adolescents are experiencing and facing which may inform future research studies on this topic and policies which may assist with an increase in adherence.

Abbreviations

Acquired Immune Deficiency Syndrome (AIDS)

Antiretroviral Therapy (ART)

Highly Active Anti-Retroviral Therapy (HAART)

Human Immunodeficiency Virus (HIV)

Medication Electronic Monitoring (MEMS)

Socioeconomic Status (SES)

Chapter 1: Introduction & Overview

1.1. Introduction

The research study described within this document aimed to explore and report the experiences of adolescents on antiretroviral therapy (ART) in the South African population, in order to understand what helps them to adhere to their medication and the challenges that they may have with adherence. This research was conducted by carrying out semi-structured in-depth interviews with adolescents at a shelter in Johannesburg. A thematic content analysis was used to analyse the transcribed interviews. There is a wealth of literature that engages with the Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) pandemic and the importance of ART and adherence. The majority of literature in South Africa on ART adherence is focused on adults and children, and not much has been done on adolescents' experiences of ART adherence, particularly not research of a qualitative nature.

1.2. Rationale

Modern medicine has brought about significant breakthroughs in the HIV epidemic. A major breakthrough is the introduction of ART and its increasing availability worldwide. In fact, between 2003 and 2008 access to antiretroviral medication in low and middle income countries rose 10-fold (WHO, 2009). The AIDS Epidemic Update (2009) reports that South Africa has the largest ART programme in the world, the consequence of which is significant public health benefits and improved access to treatment for HIV positive people. With the increase of ART availability more babies, children and adolescents are on antiretroviral treatment. Also, due to ART more babies and children born with HIV are surviving into adolescence. Studies also show that there is a high HIV prevalence within this adolescent demographic as they make up a significant percentage of new infections (Gray, 2010). However, despite the medical advances, adolescents are still a very vulnerable group. A recent study has shown that adolescents in Southern Africa are less adherent to ART compared to adults (Chaisson, Cotton, Dowdy, Hisiop, Maartens, Nachega, Nguyen, & Regensberg, 2009). This is a major concern as non-adherence on ART can increase the risk of drug resistance and morbidity. Very few qualitative studies have been done on the ART adherence of adolescents in Southern Africa. However there are related studies in Africa, such as an Ethiopian study looking at barriers and facilitators of adherence

among children (Chiunguzeni, Makwiza, Nyirenda, Phiri, Theobald & Weigel, 2009); and a mixed methods study done in Malawi assessing caregivers' knowledge, perception and attitudes towards their children's Antiretroviral (ARV) treatment (Amberbir, Biadgilign, Deribe & Deribew, 2009). Another major concern is that not much research has been done in South Africa to explore and understand the reasons that adolescents are not adhering well to ART. Several researchers have highlighted the importance of doing research on adolescence and ART adherence so that interventions can be initiated (Amberbir, Deribe, Getachew, Girma, Woldemichael, 2008; Abreu, de Oliveira, Evangelista, Filho, Hofer, Machado & Nogueira, 2008; Belzer, Durako, Moussa, Muenz, Murphy & Wilson 2005). Taking a qualitative approach to the study was vital for two reasons: the first reason was that no qualitative studies have been done in this context with this age group; and the second reason was that a qualitative study allowed for a more in-depth understanding of these adolescents' experience. The significance of the study lies in its therapeutic applications, as with a better understanding of South African adolescents' experience with ART and adherence, appropriate interventions and programmes could be set up to support adolescents living with HIV and could also encourage more in-depth research to be done in order to fully understand adolescents' experiences of living with HIV and taking ARVs.

1.3 Methodology

In order to gain a more in-depth understanding of the experiences of adolescents on ART, a qualitative design was adopted. This allowed for the opportunity to effectively explore and gain some insight into HIV positive adolescents' experiences with ART adherence. The study aimed, in particular, to explore what helps adolescents adhere to their ARV medication and the challenges they experience in adhering to their ARV medication. Due to time constraints and practical reasons this research study had a small sample size of 5 participants, which consisted of both males and females from a shelter in Johannesburg. However, the interviews were long and in-depth; hence it was felt that rich data was gained. Once consent and assent were attained the participants were interviewed and a semi structured interview schedule was used. A thematic content analysis was used to analyse the data. The results of the study present a detailed exploration of various aspects of the research topic.

1.4. Conclusion

This chapter included an overview of, and an introduction to, the research study presented in this document. Chapter 2 provides an overview of the literature pertaining to the history of HIV and ART in South Africa, ART adherence and the factors affecting and facilitating ART adherence in adolescents. This chapter contextualises the study and highlights some of the literature which has focused on adherence and adolescents' experiences with ART adherence. Chapter 3 provides a review of the literature which informed the theoretical understanding of this research study. Chapter 4 describes the methodology adopted and includes descriptions of the research design and the participants, the process of data collection, data analysis and the ethical considerations made when conducting the study. Chapter 5 reveals themes related to the participants' experiences living with HIV and taking ARVs. The adolescents' relationships to their ARVs; the integration of the ARVs into their identities; and the process of acceptance around ARTs were the predominant themes that emerged. In Chapter 6 broader reflections have been noted in relation to the research findings. Chapter 7 is the conclusion, which includes a summary of the research findings and the limitations of the research study. This chapter then concludes with recommendations and opportunities for future research.

Chapter 2: Literature Review

2.1. Introduction

The literature review covers significant content areas related to the key research interests. The literature particularly reflects an overview of the history of HIV and ART in South Africa, ART adherence and the factors affecting and facilitating ART adherence in adolescents. This assists in contextualising the study and importantly highlights some of the literature which has focused on adherence and adolescents' experiences with ART adherence across the world.

2.2. HIV and AIDS in South Africa

South Africa has one of the highest HIV prevalence rates in the world. Smit (2007) states that "the AIDS epidemic is one of the most important factors shaping social existence in South Africa" (p. 161). Statistics South Africa (2011) estimated that by 2010 there would be 5.6 million people living with HIV in South Africa. They also estimated that 10. 5% of the total population in South Africa is HIV positive and that one fifth of women in the reproductive stage are HIV positive. This also shows that South Africa's epidemic remains the largest in the world (WHO, 2010). However there also seems to be a slowing of HIV incidences and signs that safer sex practices are being used among young people in South Africa (WHO, 2010). Statistics generated from antenatal clinics also show that from 2008 to 2009 there was a slight decrease in HIV prevalence among young women aged 15-19 years and an increase in prevalence among those aged 30-34 (Avert, 2010). HIV incidence among 18-year olds declined sharply from 1.8% in 2005 to 0.8% in 2008, and among women 15–24 years old it dropped from 5.5% in 2003–2005 to 2.2% in 2005–2008 (WHO, 2010). South Africa has achieved almost 90 % coverage to prevent mother to child transmission, and due to this the transmission of HIV to infants has been reduced (WHO, 2010). This means that fewer children are born HIV positive. However it has also been found that AIDS is the largest cause of maternal mortality and also accounts for 35% of deaths in children younger than five years (WHO, 2010)). There were an estimated 330,000 under-15s living with HIV in 2009 (Avert, 2010). It was also estimated that by 2010, 1.99 million children had been orphaned by HIV (Statistics South Africa, 2011). AIDS accounted for 43% of deaths in 2010 (Statistics South Africa, 2011). It was estimated that by 2010 approximately 1. 6 million people would be in need of ART (Statistics South Africa, 2011). But

South Africa has less than 40% coverage of eligible adults receiving ART (WHO, 2010). The HIV and AIDS epidemic has affected South Africa significantly on both a macro and a micro level. An overview as to how HIV and AIDS has affected and impacted on the South African context on both these levels follows.

Starting at a macro level, it is important to look at how the government handled and is handling this epidemic. "The National response to the HIV epidemic was different to other countries like Uganda, as it has a history of contestation and often even denial of the link between HIV and AIDS" (Lush & Parkhurst, 2004, p. 1916). Systematic factors within the government played an important role in both facilitating and hindering the implementation of HIV and AIDS initiatives (Lush & Parkhurst, 2004). Starting from the time Nelson Mandela was president to when Thabo Mbeki came into power there was a lot of contestation and disagreement on the issue of HIV and AIDS and it was in fact kept out of the National Agenda (Lush & Parkhurst, 2004). In 2000 Mbeki expressed his doubt that HIV was an exclusive cause of AIDS and he argued for a consideration of socioeconomic causes (Fassin & Schneider, 2002). Schneider (2002) states that, "Mbeki's statements seem bizarre but they have a clearer logic when seen as part of an ongoing struggle between various players in South Africa" (p. 145). There were a lot of public disagreements and non-accommodation between senior African National Congress (ANC) politicians and a range of non-governmental actors in South Africa about AIDS policies (Schneider, 2002). This time was marked with disagreement on the value of ARVs and government's stalling to roll out nevirapine to prevent mother to child transmission of HIV (Fassin & Schneider, 2002). There was a lot of denial about AIDS and its effects within the government and this fed into the public's beliefs about the epidemic. On a community level the belief of conspiracy theories about HIV and AIDS was prevalent and this hindered positive behaviour change (Lush & Parkhurst, 2004). In July 2002, the Constitutional Court made a judgement ordering the government to make nevirapine available to all pregnant women with HIV, and this was followed by a cabinet statement supporting wider access to ARVs (Fassin & Schneider, 2002). This brought about a new era in South Africa. These HIV and AIDS debates brought about awareness about health inequalities and helped in mobilising people to stand up and fight for their social rights around obtaining health care (Fassin & Schneider, 2002). Political

leadership played and still plays an integral part in addressing the challenge of HIV and AIDS. South Africa now actually has the largest ART programme in the world (Avert, 2010).

HIV and AIDS in South Africa are both affected by society and affect society. Social factors such as social inequalities in income and employment status are seen as powerful predictors of infection, placing the lower socio-economic South African population at a higher risk of infection (Fassin & Scheinder, 2002). Due to a lack of income and unemployment people have a greater exposure to risky sexual experiences, lack of access to health information and prevention programmes, higher frequency of exposure to sexually transmitted infection and absent or delayed diagnosis and treatment (Fassin & Scheinder, 2002). HIV and AIDS also affect the economy and society on the micro as well as the macro-levels (Booysen, Geldenhuys & Marinkov, 2010). In 2004, the Bureau of Market Research (2004) predicted that HIV and AIDS would significantly impact household income and expenditure, and the national income in South Africa during the period 2004 to 2015. In 2004 it was estimated that a third of South African households are infected and/or affected by HIV/AIDS and that this would have a significant impact on households in South Africa and consequently on the national economy (Bureau Market Research, 2004). Collins and Murray's (2008) survey on HIV's impact on households found that 80% of the sample would lose more than half their per capita income with the death of the highest income earner and this has also changed the shape of the distribution of South Africa's prime age working population. Due to high HIV and AIDS mortality rates companies are losing labourers, especially unskilled and semi-skilled labourers, resulting in a decline in productivity and this has a direct impact on the economy as a whole (Booysen, Geldenhuys & Marinkov, 2010). The economy is also impacted through the socio-economic costs of high HIV adult mortality which includes the grave burden placed on the welfare and health care systems (Smit, 2007).

HIV has also hugely impacted society at a micro level. Smit (2007) states that the family, as a basic social unit, mainly feels the grave impact of HIV and AIDS in the society. The WHO report (2010) states that even with the decline of HIV prevalence among adults and increasing availability of ARVs in South Africa there has been no decline of children, aged 0-17 years,

orphaned due to HIV. The families are not only affected on an emotional level but also on a financial and social level. Family dynamics have been drastically changed as more and more single parent headed households result as spouses have either deserted the family or been killed by AIDs; grandparents are having to parent their grandchildren whose parents have died from AIDS; an increase of child headed households is being found as parents have passed away due to AIDS; and there is a shift away from the nuclear family as families are relying more on the extended family to care for them when they are ill and, or take their children in when they die (Smit, 2010). "However one of the key obstacles to communities' capacity to care has been the stigmatisation of the infected; a defence mechanism used by the community... which can lead to the social quarantine of the potential contaminant" (Barolsky, 2003, p. 25). This is a major problem for families as they are shunned by their own neighbours and community instead of getting support from them. However stigma is also found within the family. A South African study found that children were afraid to disclose their status to their own parents as they worried they would be stigmatised by them (Campbell, Foulis, Maimane & Sibiya, 2005). This study also found that some families hide away sick relatives, depriving them of health care and support, or they disown dead relatives and refuse to go to claim their bodies at the mortuary. Even sick relatives do not ever talk about having AIDS. Stigma is a real problem in the South African community and it often prevents people living with HIV and AIDS from being tested and/or accessing treatment.

HIV and AIDS pose great challenges to the futures of South African children. They have to take on adult household responsibilities, such as taking care of the ill and dying and finding work to support the family, which often results in them missing out on an education leaving them at risk of destitution (Booysen & Arntz, 2002). Studies such as this also show that due to HIV, more and more children are being left orphaned and as a result they are 'bounced' from one family member to another (Smit, 2010). Due to this, the extended family, such as grandparents, have had to play a significant role in taking care of these orphaned children. This has positively influenced the government to roll out an initiative of child support grants to more households, to roll-out home-based care to more affected households, to develop alternative and innovative models of community-based orphan care, and to increase awareness and protection of the rights

of women and children (Booysen & Arntz, 2002). The AIDS epidemic has had a significant impact on the South African society at a national, community and individual level. HIV and AIDS has also left a great many South African children vulnerable and at risk.

2.3. Antiretroviral Therapy Adherence

The introduction of ART has brought about significant change in extending the lifespan and the quality of life of people living with HIV or AIDS (Amberbir et al., 2008, Abreu et al., 2008). Research shows that ART has and is considerably improving the lives of children in Africa; however excellent adherence is mandatory for treatment success (Boulle, Davies, Eley, Fafir & Nuttall, 2008). ART adherence is one of the major concerns in the public health sector. Highly Active Anti-Retroviral Therapy (HAART) is very important as it can lead to the suppression of HIV virus type 1plasma viremia to undetectable levels for more than three years or more (Belzer, et al., 2005). ART is clearly very important for people living with HIV or AIDS; however, for it to be effective one has to adhere to the medication.

ART and adherence go hand in hand for optimal results. The definition of adherence is the extent to which a patient takes their ART as prescribed and required by their medical practitioner or health care provider (Belzer et al., 2005). However adherence is far more than taking medication, it is more of a lifestyle. Adherence is a treatment process and a patient has to be an active member in that process; health care providers believe that it is more than taking one's medication, but is also about following a diet, and or executing lifestyle changes (WHO, 2003). ART treatment is a long term treatment plan of HIV/ AIDS and requires the patient to have at least 95% adherence to prevent the emergence of drug resistance (Belzer et al., 2005). High levels of adherence are essential for optimal benefit of ART. Several researchers have highlighted issues of poor adherence and non- adherence, which is when a patient is not taking their medication as advised by their health care provider (Farley, Kammerer, Malee, Montepiedra, Nichols, Sirois, Storm & Williams, 2006). ARV medication has to be taken every single day at the same time for the rest of the patient's life for the simple fact that the disease process is chronic and ARVs manage and suppress the virus (WHO, 2010).

There are several methods used to measure if a patient is adhering to their ARV medication. Researchers use different indicators to measure adherence. The first is that adherence can be measured by counting if the patient has missed a dose of medication or skipped a day of medication, and also whether the patient has missed medical appointments (Bell, Bell, Camacho, Henry-Reid, Martinez, Rodriguez & Watson, 2000). Other methods to monitor adherence are through measuring the patient's HIV-1 RNA viral load, through using a medication event monitoring system (MEMS), and through monitoring behavioural factors associated with ART adherence (Belzer et al., 2005) such as: re-fulfilment of medication and dietary requirements associated with ART (WHO, 2003). There are also many factors that are used to predict adherence and some are considered unreliable. Patient report is considered unreliable as patients tend to overestimate their adherence levels so other tools are used in conjunction with this such as pill re-fulfilment as a way of predicting adherence (Boulle et al., 2008). However pill re-fulfilment is also unreliable because even if a patient has refilled their treatment it does not guarantee that they are taking their medication (Boulle et al., 2008). It is suggested that using questionnaires that ask about specific behaviours relating to treatment recommendations (e.g. dietary and nutritional patterns, healthy living and management of weight) may be better predictors of adherence behaviour (WHO, 2003). Pill counting is another strategy that is used but it is also not reliable as this cannot measure whether a patient is following time schedule requirements; hence, a medication electronic monitoring (MEMS) device was invented, which records the time and date when a medication container was opened, therefore better monitoring the way patients take their medications (WHO, 2003). This innovation is essential and could make a difference with adherence measurement, but unfortunately it is expensive and therefore is not widely available. Another innovation used to measure adherence is non-toxic biological markers that are put into the medication and then their presence is tested in blood or urine, which will inform the practitioner if medication is being taken. Unfortunately this too is not adequate as the findings can be influenced by a number of factors such as diet, absorption and rate of excretion (WHO, 2003). It is clear that there are several methods used by both practitioners and researchers with varying levels of reliability and cost-effectiveness. However if multiple approaches are used then adherence measurements could possibly produce more accurate adherence levels. As mentioned earlier adherence to ART is one of the greatest challenges in the

public health sector with the management of HIV and AIDS; and it is very costly as a large amount of the treatment goes to waste (Belzer et al., 2005, WHO, 2003). It is reported that in developed countries, adherence to long-term therapies in the general population is around 50% and is much lower in developing countries (WHO, 2003).

There are numerous reasons why adherence is such a concern and these will be reviewed next. Excellent adherence is one of the most important factors in achieving ARV treatment success and preventing drug resistance to drug regimes (combination of ARV medication) (Boulle et al, 2008). There is a major concern for the public health sector that non- adherence to drug regimes may advance the emergence of drug resistant strains of HIV, which will consequently aggravate treatment for adults, children and adolescents living with HIV or AIDS (Bell et al., 2000). Drug resistance is a major concern in relation to the AIDS epidemic for the following reason: if a patient does not take their ARVs as they should, this results in there being low levels of medication in the body which cannot suppress the virus; once the virus is not suppressed it builds strength and it is able to adapt to the workings of the ARVS resulting in the virus becoming resistant to the ARVs, making them ineffective. If a drug resistant strain of HIV emerges there may be a spread of HIV that is not susceptible to ARV treatment. Non-adherence can also result in morbidity and mortality which is another major issue for both patients and the health sector (Bell et al., 2000). If the treatment fails then the patient has few options, and if there is nothing to suppress the virus the patient is at risk of developing AIDS which could eventually kill him or her.

There are a significant number of adolescents in Southern Africa who acquired HIV prenatally, and evidence shows that they contribute significantly to hospital admissions and in-hospital deaths (Gray, 2009; Ferrand et al., 2010). Statistics show that 85 % of 2.5 million HIV- infected children under the age of 15 years worldwide are from the sub-Saharan African region (Boulle et al., 2008). The other issue is that the availability of second-line and antiretroviral therapy regimens in sub-Saharan Africa is limited and maintaining the first line of ART is crucial, more so for adolescents who are expected to live longer due to ARV treatment (Chaisson et al., 2009). This clearly shows that there is still an urgent need to provide access to services and increase the

availability of ART and support for adolescents living with HIV. Adolescents are considered to be the most likely to benefit from ART and if they are not adhering well as studies show, this could be a major crisis. There are gaps in the research in relation to adolescents and ART adherence in South Africa; very few studies have been done to understand the experience of these adolescents and their understandings of ART adherence. However, before one can explore what they are experiencing it is vital to understand their developmental stage as a whole. This will be explored in the next chapter.

2.4. Factors affecting and facilitating Adolescents and ART Adherence

Despite the medical advances that are being seen, there are still some social aspects that are affecting the wellbeing of adolescents living with HIV. Studies are clearly showing that this age group is not adhering to ARV medication and this is of major concern as non-adherence to ART can increase the risk of drug resistance and morbidity (Gray, 2009). As mentioned above, adolescence is generally a difficult stage of development and being HIV positive and having to be on a long term treatment adds to the burden (Chaisson et al., 2009). A longitudinal study from thirteen states in the USA identified that factors associated with poor adherence among adolescents included depression, pill burden, advanced HIV status, alcohol use, dropping out of school, side effects and complications of day-to-day routine (Belzer et al., 2005). Belzer et al. (2005) suggest that the reason these adolescents could not adhere effectively during the late stages of the disease is most likely due to the fact that they are possibly more affected physically, thus being less able to tolerate the adverse effects of medication, or it could be owing to their depression over disease progression and lowered outcome expectations that the medication can be helpful to them. Ridder, Geenen, Kuijer and Van Middendorp's (2008) review also found that with chronic illnesses the malaise imposed by physiological processes of the illness has an effect on adjustment to living with a chronic illness.

A qualitative study in Uganda found structural factors like poverty and stigma as barriers to ART (Atuyambe, Kasasa, Neema, Otolok-Tanga, Wabwire-Mangen & Wamuyu-Maina, 2009); internalised stigma is identified as being associated with important health outcomes such as delays in pharmacy refills and medical care (Chirwa, Dlamini, Greeff, Holzemer Kohi, Makoae,

Mullan, Naidoo, Uys & Wantland, 2008). According to these findings, if a patient perceives that they will be discriminated against due to their status, they avoid getting medical care. Studies also found that the most common issues associated to poor adherence were psychosocial problems, and lack of help for these issues, erratic drug taking, and lack of disclosure of HIV status (Amberbir, Biadgilign, Deribew & Deribe, 2008; Ferrand et al., 2009; Farley et al., 2006). The psychosocial problems for adolescents in these studies were stigma, delayed disclosure, difficulty in identifying with HIV- negative peers and a desire to conform, anxiety about sexual relationships and future planning, and low self-esteem and feelings of hopelessness; which were compounded by the adolescent having to head a family, and having to take care of ill relatives and siblings (Chiunguzeni et al., 2009; Ferrand et al., 2009). The issue of stigma is linked to various issues, such as when the main caregiver is away there is fear of disclosure and some caregivers face difficult decisions about whom to ask to support drug adherence for their child in their absence; or the death of a caregiver, leaving no one to administer ARV treatment to the child; or even the child being away visiting relatives could cause problems in adherence to drugs, as the responsibility is then left to the child (Chi et al., 2009; Chiunguzeni et al., 2009).

There is much debate on whether socioeconomic status (SES) has an effect on ART adherence (Amberbir et al., 2008). Orrell et al. (2003) found that low SES was not a predictor of adherence for patients getting their therapy for free; which was shown in this particular study by adherence in developing countries being at least as good as adherence in developed countries. However several studies show that components of SES play a role in poor adherence. Fennell, Leitz and Fantauzzi (2012) indentified that education, poverty and living with a chronic illness are intertwined as children are at a higher risk of absenteeism and some drop out due to their own or a family member's chronic illness. They miss out on too much foundational knowledge which is overwhelming, frustrating and difficult to catch up and/or understand (Fennell, Leitz & Fantauzzi, 2012). Lack of education is identified as a major cause of a lifetime of poverty and poor health (Fennell, Leitz & Fantauzzi, 2012). This also indicated the importance of educational institutions addressing the lack of standardised protocols and policies to accommodate chronically ill students and their families, in order to contribute toward their long-term economic security and health (Fennell, Leitz & Fantauzzi, 2012). The absenteeism at school can be due to

doctors and medication appointments or even the illness itself such as relapsing. Issues associated with SES that were found to impact on adherence were the inability to afford transport fares and food, which resulted in missed medical appointments and malnutrition (Amberbir et al., 2008; Ferrand et al., 2009). In the USA, studies show that adolescent's living situations can impact on adherence. These challenges included: their family structure; homelessness; being marginally housed; having unstable lives; needing help with basic daily living skills such as income generating, planning and eating nutritious meals; finding a regular place to sleep and live; and their parents or guardians struggling to care for themselves and sometimes even their own children, circumstances in which medical treatment and adherence is often the last thing on their minds (Bell et al., 2000; Farley et al., 2006). Farley et al. (2006) identified that older adolescents have an increased likelihood of non-adherence, and caregivers must be careful with giving the adolescents too much responsibility; as this may be premature for some, given that some adolescents with HIV infection may have cognitive or emotional difficulties that influence their ability to function independently, unlike their HIV negative peers. At the same time, they are facing the normal challenges of adolescence that may affect their willingness and, or ability to assume important health maintenance behaviour, such as medication adherence (Farley et al., 2006). Chronic illness has been found to have an effect on behavioural, cognitive, and emotional challenges of disease and also coping with these physiologically-induced symptoms (Ridder, Geenen, Kuijer & Van Middendorp, 2008), making it necessary to always take note of this particularly with adolescents.

The other factors that studies have identified as affecting adherence are as follows: in Brazil patients would not carry extra doses of medication while out of the house and therefore would miss a dose (Abreu et al., 2008); the other association to adherence was the relationship patients had with their health care provider and level of education and understanding of ART and unhealthy lifestyles (Abreu et al., 2008). Some patients reported skipping doses because of simply forgetting; feeling sick or ill (sometimes due to side effects of medication); being busy and running out of medication; and also due to a lack of social support (Amberbir et al., 2008; Abreu et al., 2008). Research across the world has shown that it is very clear that there are a range of reasons why adolescents are failing to adhere to treatment. Adolescents living with HIV

are becoming a booming population and they are a major concern in the world and more so in Southern Africa. Unfortunately, insufficient research has been done in South Africa to explore what HIV positive adolescents are experiencing with ART adherence, especially from a qualitative approach. This is the area that this study will cover; exploring the adolescents' experiences and trying to discover what they understand about ART adherence and also the challenges they experience with ART adherence; because only until their experiences and challenges are understood can appropriate initiatives and interventions to support and address adolescents' needs be established.

As highlighted above there are several factors that challenge ARV adherence, however, research shows that there are also factors that facilitate ARV adherence (Dahab et al., 2008; Watt et al., 2009; & Nachega et al., 2004). A study conducted in Los Angeles identified that making a commitment, routinising, health beliefs, social support, and professional support facilitate ARV adherence (Roberts, 2000). This research found that medi-sets (pill cases compartmentalised into days of the week and, or doses during the day), alarm clocks, written notes and day planners remove the burden of having to remember complex medication schedules which is common to ARV regimens (Roberts, 2000). Medi-sets were also found to reduce medication mistakes such as double dosing or missing a dose which can happen when using the normal pill bottles. However it was also identified that some people were concerned that there may be some stigma associated with using the medi-sets (Roberts, 2000). People worry about what other people will say or think if they take out their medi-sets in public areas and this can result in one missing their doses. However medi-sets clearly assist with when and how one should take their medication. It was also found that one's mindset, self discipline and commitment to taking their ARVs are helpful to adherence (Roberts, 2000). Research has also found that good adjustment predicts increased participation in self-management and vice versa (Ridder, Geenen, Kuijer & Van Middendorp, 2008). So if one can adjust or come to terms with living with HIV then they engage in more self care behaviour which befits them on a physiological and psychological level. Another facilitator that assists with commitment to ones ARV medication is routinisation of the medication schedule. Routinisation is when the person incorporates their medication taking behaviours into their day-to-day routine (Roberts, 2000). A way of doing this would be for a

person to incorporate taking their medication into activities they generally would be doing like waking up, eating breakfast, going to school or work and dinner time. Research also shows that if one believes that the medication is working and making a positive change in their health, they become more invested and motivated in taking the medication (Mills et al., 2006). In relation to this; people were also motivated to adhere to their ARVs when witnessing their friends or family members getting sick or dying, as they did not want the same thing to happen to them (Roberts, 2000). One's attitude also tends to have an influence on adherence. These included acceptance of HIV status, having faith in the treatment, high self-worth, self-efficacy and a desire to live (Mills et al., 2006). Another important influence on psychological adjustment to and the self-management of a chronic illness is psychiatric conditions such as mood disorders (Ridder, Geenen, Kuijer & Van Middendorp, 2008). Thus it is important for clinicians to keep an eye on this and manage these disorders if they are present, as they can affect ones attitude, behaviour and cognitive processes to living with HIV. Social support is also identified as being a strong motivator for adherence. Family and friends that facilitated with adherence were also found to be helpful. This support included: reminding them to take their medication, refilling their prescriptions, and helping to provide and cook the appropriate meals to take with medication (Murphy, Marelich, Hoffman & Steers, 2004). Roberts' (2000) study also found that some patients would borrow medication from their friends or family when they did not have any with them. Research also found that people who had a good relationship and were able to communicate with their health care provider were more likely to adhere to their ARVs (Murphy, Marelich, Hoffman & Steers, 2004). The more they trusted and believed in what their health care provider was saying, the higher the chance that they would listen to their healthcare provider and adhere to their medication.

Within children's experiences of living with HIV and adherence to ARVs, disclosure seems to play a very significant role as well. Informing a child or adolescent of their HIV status is a difficult task, however, the time always comes when disclosure has to be done. It has been reported that there are both negative and positive social, psychological, and behavioural impacts to disclosing to a child their status. One of the impacts includes improved adherence (Vaz, Eng, Maman, Tshikandu & Behets, 2010). This study showed how parents worry that if they disclose

to the child, the child will react negatively and some worried their child would harm him or herself after disclosure. The most common motivators for full disclosure to the child are due to medication reasons; either because they were not taking their medication properly or because they were about to start their regime, to prevent siblings from getting infected and the child's will to know their illness (Vaz et al., 2010; Azondekon et al., 2005). Writing about terminal illness, Kubler-Ross (1970) writes that the question should not be "should we disclose?" but rather "how should we disclose". She further adds that when disclosure is done properly by a physician then the patient will not feel fear isolation, deceit and rejection but will rather have confidence in the honesty of his physician and also have the hope that if there is anything to be done it will be done. Abadia-Barrero and Larusso (2006) conducted a study in Brazil and they also found that lack of communication about HIV and AIDS creates a context of confusion and mistrust, and that self-stigma is detrimental to psychosocial development and coping, compromises disease knowledge, and increases vulnerability to risky behavior. It seems that a lack of disclosure causes more harm than good. The American Academy of Paediatrics (1999) report that children who know their status have a higher self esteem and better coping skills to those who are unaware of their status, but are ill or on medication. They also report that not disclosing to the child can have the negative consequence of them developing inappropriate negative fantasies about their illness and may also isolate them from potential sources of support. With children and adolescents it is important for the family and the heath care provider to collaborate in how to disclose to the child (Vaz et al., 2010). Studies show that disclosure may have an initial negative response but on a long term basis it seems to benefit the child and adolescent. Disclosure allows for them to take up a more active role in their health such as adhering to the medication, and it also opens up the space for communication and them seeking the support that they need to be able to process, come to a place of acceptance and manage and cope with their illness.

Several studies have also been done in developing countries on barriers and facilitators of adherence and these include Brazil, Tanzania, Peru, Ethiopia and South Africa. A study identified adherence as being higher in developing countries than in developed countries and it is vital to explore why that is (Watt et al., 2009). This however is contradictory to other studies

mentioned previously, such as that conducted by Orell et al. (2003). These contradictory findings serve to illustrate the need for further research to be done in this area. A study done in Tanzania identified five main factors that facilitate ARV adherence (Watt et al., 2009). The first factor was the people's confidence in ARVs after experiencing improvements in their health (Watt et al., 2009). The second factor was people's perceptions of their responsibility to their family, for example, parents wanting to live to take care of their children and also being around to see them grow up (Watt et al., 2009). The third factor was material support; such as food and money, and emotional support from family, friends and counsellors from their health centre (Watt et al., 2009). The fourth factor that Watt et al. (2009) found was strategies used to remember to take pills, such as routinising pill-taking by linking it with day to day activities or events as was discussed earlier. The last facilitator identified in this study was a person's relationship and trust in the advice of health care providers (Watt et al., 2009). A study done in Ethiopia focused on the facilitators of adherence in children and they found these to be: mobiles or wall alarms, ongoing counselling to caregivers on adherence, improved health and quality of life in the child, child friendly ART clinic setups, and disclosure of HIV to children (Amberbir, Biadgilign, Deribe & Deribew, 2009). Facilitators for adherence in children are closely linked to the child's caregivers as they are responsible for making sure ART is adhered to, but also for making the child aware and involved in adherence.

Studies have also been done in the South African context. A qualitative study done on a workplace program in South Africa found that disclosure, having social support and a strong belief in the value of treatment facilitated adherence (Dahab et al., 2008). Another study conducted in KwaZulu-Natal found that people with higher CD4 counts and better perceptions of their health had increased adherence. More positive attitudes about life and fewer worries about dying; higher social support scores and experiencing less discrimination were also found to be predictors of adherence (Anderson, Peltzer, Preez & Ramlagan, 2010). A study done on adults in Soweto showed that they had excellent adherence and it also found that affordability of medication and HIV and AIDS education programs that help to decrease disease stigmatization maximise adherence (Nachega et al., 2004). Another factor highlighted in a review of psychological adjustment to chronic illness identified that for some benefit finding once

diagnosed with a chronic illness can help with psychological adjustment and living with chronic illness (Ridder, Geenen, Kuijer & Van Middendorp, 2008). It is however also important to assess that the benefit finding is not being used as a defence mechanism which can hinder the process of psychological adjust and acceptance of one's illness. As highlighted in this section, facilitators of adherence are an integration of social and personal factors. It is clear that adherence is possible and can be achieved. However most of these studies focused more on adults or children and it is vital to also look at what helps adolescents to adhere to their ARTs in our community.

2.5. Conclusion

HIV and AIDS is a vast topic with various foci and thus there is a vast array of literature on HIV and AIDS. This literature review chapter started off on a broad level by trying to better conceptualise the issue of HIV and AIDS in South Africa. To accomplish this HIV was discussed in relation to the progression of the political, social and economic impact of HIV and AIDS in South Africa. The next focus was to highlight and discuss the issue of antiretroviral therapy adherence which is a part of the focus of this study. This chapter then highlighted some literature on factors affecting and facilitating adolescents' ART adherence, particularly the factors that inhibit appropriate adherence and what assists adolescents with good adherence. There was not much research that was found on adolescents ARV adherence in South Africa, hence the motivation for this inquiry.

Chapter 3: Theoretical Framework

3.1. Introduction

The theoretical framework includes a review of the literature which informed the theoretical understanding of this research study. The literature includes some theories of the development of adolescents, theories on identity formation, which is also an important area of development in adolescence, and lastly the chapter provides literature on a variety of defence mechnisms and ways in which people cope with and come to terms with living with a chronic or terminal illness as this can be highly challenging for HIV positive adolescents.

3.2. Adolescence

To understand the stage of adolescence it is vital to look at theories on development. There are diverse theories which take different approaches to understanding adolescence as a developmental stage. These theories provide us with a deeper understanding of how adolescents act, why they act in a certain way, and how this affects the way they develop. Hall (as cited in Balk, 1995) stated the stage of adolescence as a time of storm and stress; and psychoanalysts kept this view alive, and in this section there will be discussion on some theories on the development of adolescents.

Sigmund Freud developed three concepts: the unconscious, defence mechanisms and the stages of psychosexual development. The unconscious is made up of three mental processes: the id (its purpose is to achieve pleasure and the individuals purpose is to keep it under control); the ego (its purpose is to develop mental processes that allow an individual to be able to simultaneously meet the demands of the id and the expectations of the external world); and the superego (this develops between age 5 and 6 and its purpose is to internalise the expectations of parents or caregivers; in other words the individual develops a conscience) (Balk, 1995). Freud believed that the id, ego and superego are fundamental to how an individual develops and interacts with the self, others, and the world (Balk, 1995). The second concept Freud developed is defence mechanisms; also known as operations of the ego to prevent an intrusion of the id. There are ten examples of defence mechanisms and some of them are repression, intellectualization and projection (Balk, 1995). The purpose of the defence mechanisms is to assist the ego to cope with

anxiety, frustration, and unacceptable impulses and help relieve tension and inner conflicts (Lemma, 2003). The third concept is Freud's stages of psychosexual development. Freud suggested that there are five psychosexual stages: oral, anal, phallic, latency and genital (Naidoo, Townsend & Carolissen, 2008). Rather than discussing all five stages, this paper will only be looking at the genital stage as that is the stage relevant to adolescence. Freud believed that this stage begins with puberty, which marks the start of adolescence (Lerner, 2002). He believed that during puberty males become more interested in sexual intercourse and seminal discharge, where as females experience a strengthening of sexual inhibitions. A South African study identified that almost two-thirds of both rural and urban adolescents have had sexual intercourse (Peltzer, 2006). This study also showed that urban female adolescents take more initiative at first sexual intercourse than rural female adolescents (Peltzer, 2006). Another study in South Africa showed how gender influences developmental changes among the youth by inhibiting their self-confidence, access to information, and opportunities to acquire skills; differences between male and female determine the power dynamics that influence the way girls and boys experience intimacy, sexuality and reproduction (Maluleke, 2007). This particularly poses some difficulty with HIV positive adolescents as they have to worry about issues of disclosure of their status to their partners and safety measures required during sexual exploration and intercourse. Freud's view is that turmoil and turbulence mark adolescence because unconscious prohibitions are raised against releasing tensions brought about by puberty (Balk, 1995). He also believed that adolescents are narcissistic; meaning that an adolescent is infatuated with the self. This narcissism is said to strengthen the adolescent's egos attachment to ideals; meaning that they eventually go beyond selfish interests in immediate gratification and form ego ideals which include social institutions like the family (Balk, 1995). HIV positive adolescents all across the world often are the ones left in charge of taking care of their parents and their families, so moving beyond one's selfish needs has to occur whether they are ready for it or not.

Anna Freud believed that adolescence is a time of developmental disturbance and a period of turmoil (Lerner, 2002). She believed during the latency stage an individual's development is stormy and stressful (Lerner, 2002) as the balance between the id, ego, and superego that was achieved previously is discarded during puberty, leading an individual to a new internal

adjustment. According to Anna Freud this upheaval is necessary for an adolescent to be able to incorporate a mature sexual identity into his or her personality (Balk, 1995). She felt that if an adolescent did not go through this upheaval then they were not making the necessary internal adjustments; therefore they were not developing in an appropriate manner. Anna Freud actually viewed this stage as an abnormal time in one's life.

Blos (as cited in Balk, 1995) used Freud's concepts of the id, ego, superego, Oedipus complex, defence mechanisms, and the five psychosexual stages, and also wrote about the stage of adolescence as a time of turmoil and stress. He believed that with regards to a person's psychological development, maturity can only be attained through conflict (Blos in Balk, 1995). Blos (as cited in Balk, 1995) also described adolescence as a time of vulnerability, ambivalence, and conflict. He suggested that there are four phases of adolescent development: preadolescence, early adolescence, adolescence proper (middle adolescence) and late adolescence. The preadolescence phase is the period before the onset of puberty. According to Blos (as cited in Balk, 1995), during this time the adolescent is experiencing psychic imbalances because their instinctual demands (the id) are revived and are confronted with disapproval from the ego and superego. Due to this conflict the adolescent then regresses to their earlier forms of development (Balk, 1995). Blos (as cited in Balk, 1995) stresses that this stage is crucial for all of the adolescence process as it sets the stage for resolving the developmental challenges that materialize later in adolescence. Early adolescence is marked with a lessened identification with parents, increased identification with peers, intense involvement with causes, infatuations with an opposite-sex peer. Blos says that adolescents try to form new ego ideals that are separate from dependency on parents, form more heterosexual relationships and develop a mature identity; failure to achieve ego ideal results in a permanent barrier to maturity (Balk, 1995). This can be particularly hard for adolescents living with HIV because as well as trying to cope with the normal challenge of identity formation in adolescence; they are also trying to find ways to cope with an HIV-positive identity. The adolescence proper phase is coupled with detachment from the parents, and development of a distinctive, and mature identity. A study in South Africa showed that adolescents' perceptions of sexuality included developing trust in themselves, and at the same time seeing parents and other adults as backwards and old-fashioned people (Maluleke,

2007). This supports Blos's theory that adolescents move away from their parents to try and form their own identities. In this phase the adolescent is also trying to resolve the Oedipus complex which according to Blos is the second individualisation process. He states that during this period the superego is altered substantially. He also states that during this phase adolescents regress; as they revert to earlier forms of coping. Blos however did not view this regression as a negative thing but rather that it was normal and necessary for the adolescent to mature (Balk, 1995). This regression is therefore needed for development. Late adolescence is when an adolescent realises that striving towards the ego ideal is a never ending process which is necessary and important for their development. The end of this phase is also the emergence of a stable character formation which can be achieved by meeting distinct developmental challenges; dealing and coping with traumatic experiences; being able to accept ones past and being able to move forward and have a future (this can be difficult if defence mechanisms prohibit that). The last developmental challenge is the emergence of the sexual identity (Balk, 1995). Beginning to negotiate one's sexual identity and relationships can be difficult for any adolescent, more so for those living with HIV as they have to worry about issues of disclosure, stigma and taking extra precautions if they want to engage in sexual intercourse. Blos agrees with Anna Freud that adolescence is a time of conflict and turmoil, but differs with her in considering adolescence an abnormal time in life (Balk, 1995). He considers the turmoil normative and takes the stance that this conflict and turmoil is important for increasing maturity, individuality and independence.

Erik Erikson took a different approach to the above three theorists. He developed the psychosocial model. The psychosocial model proposes that psychological development occurs because the individual must adapt to society's demands and expectations (Lerner, 2002). This model proposes that psychological growth occurs because of conflicts that are specific to the human species. Erikson believed that there are eight stages of development, known as Erikson's eight ages of man and that in each of these stages there is a crisis that society expects one to master (Balk, 1995). Erikson's eight ages of man are: Infancy, Early Childhood, Play Age, School Age, Adolescence, Young Adulthood, Adulthood and Old age. This section will only cover the stage of Adolescence. Erikson states that "during adolescence the crisis is between developing a sense of identity (e.g. knowing one's role in society, and knowing what one

believes) versus role confusion or role diffusion (e.g. not knowing what one can do with oneself in society, and what one believes in)" (Lerner, 2002, p. 45). He believed that during adolescence the major challenge is for one to achieve fidelity in one's commitments while retaining diversity at the same time. Basically the adolescent would have to find a balance between fidelity and diversity. Erikson states that during this stage there is rapid physical development causing the adolescent to be self conscious (Balk, 1995). They worry more about what other people think about them than self evaluation. Erikson like Blos believed that during this stage there is an emergence of a new ego identity, but unlike Blos he also thought there was an integration taking place in the form of a new ego identity (Balk, 1995). Gibson and Rohleder (2005) state that the 'self' is continuously shaped through the prevailing social discourses and construction of meaning. Therefore, for an HIV positive person, whatever negative meanings or beliefs are adopted by their communities about HIV may be integrated into the construction of their self identity (Gibson & Rohleder, 2005). HIV positive adolescents' identity formation may be particularly difficult as they are subject to societal stigma and discrimination that surround HIV and AIDS which may impact on the development of their identity.

The psychosocial approach basically stipulates that there are five main sets of developmental issues during adolescence: identity, autonomy, intimacy, sexuality and achievement (Steinberg, 2005). Erikson went as far as stating that the greatest threat to an adolescent achieving resolution of the developmental crisis of adolescence is the inability to choose and settle on an occupation (Balk, 1995). He believed that the need to find an occupation went beyond a desire for lots of money, achievement or approval from society, but rather they would be victims to role confusion if they did not settle on an occupation (Balk, 1995). Blos and Erikson have more positive views of adolescent development in that they believed that this was a time for self discovery and finding a purpose and interest in life which is a natural process, where as Sigmund Freud and Anna Freud thought adolescence was a time of turmoil and psychopathology (Balk, 1995). All adolescents even those who are living with HIV, face difficulties of a personal nature, such as self-awareness, defining their identity, building their peer group, making plans for the future, and dealing with their sexuality (WHO, 2009). This is a stage where they are taking the step from childhood into adulthood and this is hard in a variety of ways and causes inner conflicts such as

stress, confusion, and an identity crisis. As mentioned earlier, adolescents strive for autonomy and independence but adopting conventional theories of how adolescents develop is not always applicable for HIV positive adolescents as they do not always develop like their HIV negative peers and they have many stresses and burdens that affect their development both physically and psychologically.

3.3. Identity Formation

This section will be looking at the issue of identity formation as this process is also quite critical during adolescence. Coupled with this is also the challenge of trying to integrate being HIV positive into the process of identity formation. Identity formation involves a process of crisis/ exploration and commitment to sexual orientation, an ideological stance, and a vocational direction which occurs more gradually and unconsciously (Marcia, 1968). Marcia (1966) referred to "crisis/exploration as the period when the adolescent actively examines developmental opportunities and identity issues. Commitment pertains to the degree that the adolescent is personally involved in, and expresses allegiance to, self-chosen aspirations, goals, values, beliefs, and occupation" (as cited in Hosek, Harper & Robinson, 2002 . p. 355). An important issue during adolescence is when adolescents are trying to figure out their identity; a process of exploration where they try to discover who and what they might be. This process of exploration and commitment to an identity and the consolidation of this process is what underlies the formation of an identity (Berman, Schwartz, Kurtines & Berman, 2001). Marcia (1968) viewed:

> Identity as a self-structure; an internal, self-constructed, dynamic organisation of drives, abilities, beliefs, and individual history. He further writes that the better developed this structure is the more aware individuals appear to be of their own uniqueness, similarity to others and their own strengths and weaknesses in making their way in the world. The less developed this structure is the more confused individuals seem about their own distinctiveness from others and the more they have to rely on external sources to evaluate themselves (p. 159).

Erick Erickson (1968) believed that identity issues could be present at any stage of one's life; however, he saw identity formation as the critical developmental task of adolescence. Marcia (1968) also writes that:

> Adolescence is a period more crucial for change in structural form; a period of transition in approach to cognitive (from concrete to formal operations); in approach to moral issues (from law-and-order (duty) reasoning to transcendent human values); in approach to psychosocial concerns (from others' expectations and directives to one's own unique organisation of one's history, skills, shortcomings, and goals) (p. 160).

This process that characterises adolescence and which makes up the formation of one's identity appears to involve a number of tasks. Adolescents have to relinquish their parents for larger psychosocial concerns; and move from others' expectations and directives to their own unique organization, based upon their own histories, skills, shortcomings, and goals. For some adolescents achieving identity is difficult as it is hard for them to let go of the past which is known and delve into the unknown, uncertain future (Marcia, 1968). In other words identity formation is a process of self discovery where the adolescent is trying to determine who they are and who they want to be, in a process of trying to gain their independence, and this can be a difficult and scary as it demands going into the unknown.

Marcia (1968) conceptualised the four identity status theory, intended for characterising an individual's exploration and commitment in the development toward a mature identity. Elaborating Erikson's psychosocial stage of identity achievement vs. identity diffusion, the four statuses are: Identity achievement, Moratoriums, Foreclosure, and Identity Diffusion. This allowed for Erikson's theoretical notions about identity to be subjected to empirical study (Marcia, 1968).

> Identity achievement describes someone who has experienced a decision-making period and are pursuing self-chosen occupation and ideological goals (crisis and commitment are present). Moratoriums describe people who are currently struggling with occupational and, or ideological issues (they are in an identity crisis with vague

> commitment). Foreclosures describe people who are committed to occupational and ideological positions. But these have been parentally chosen rather than self-chosen (they show little or no evidence of crisis and commitment is present). Identity diffusion describes young people who have no set occupational or ideological direction, regardless of whether or not they may have experienced a decision-making period (crisis present or absent and commitment absent) (Marcia, 1968 .p. 161).

These statuses provide us with a variety of identity styles which allow for a broader understanding of the process of identity formulation. The statuses also highlight the presence of an identity crisis and explore how committed individuals are in the process of consolidating an identity. Disability or chronic illness can complicate identity formation and may cause a feeling of flawed identity in an adolescent (Chigier, 1992; as cited by Hosek, Harper & Robinson, 2002). It is thus important to then look at whether the experience of living with HIV and taking ARVs may have an effect on the adolescent's process of identity formation. Hosek, Harper and Robinson (2002) conducted a qualitative study which explored the issues of adolescent development, particularly identity development, and how this process may be affected by the presence of HIV. They found that all the participants fell into either Diffusion or Achievement identity statuses, which in turn impacted their response to having HIV. The two identity statuses represented here fall on the opposite ends. This might indicate that for some, the HIV diagnosis helped to facilitate and further the identity development process, while for others the opposite occurred and the possibility that their life is limited, and fear of setting goals that might not be achieved, inhibited exploration of identity issues and promoted the avoidance of commitment (Hosek, Harper & Robinson, 2002). There is not much research that has been done of the effects of HIV on adolescence identity formation, but these studies, however, have shown that having a terminal or chronic illness has some impact on this process and it is vital for this area to be adequately researched.

3.4. Defences and coping with a chronic or terminal illness

An HIV diagnosis can be experienced as a loss and as a trauma, as one has to grapple with the reality of having a chronic or terminal illness and possibly premature death. This section will highlight some of the literature which looks at how people manage the reality of possible death.

Kubler-Ross (1970) writes that death has always been distasteful to man and will always be and this is because to the unconscious mind, death is never possible in regard to ourselves. However when it comes to a chronic or terminal illness the possibility of death has to be faced, which is a very difficult reality to be confronted with and one that often evokes activation of intrapsychic defences. "Defences are an unconscious function of the ego in where they falsify, negate or distort reality so to avoid anxiety provoking situations, through denial, avoidance or transforming ideas and their associated affect" (Lemma, 2003, p. 206). Ridder, Geenen, Kuijer and Van Middendorp's (2008) review also identified consequences of chronic illnesses which is a new experience to patients and challenges their habitual coping strategies which forces them to come up with new ways of coping with the adjustment. This process of adjustment and coming to terms with one's illness can be a 1ong process. Having to face and accept possible death and living with a chronic illness can be challenging and Kubler-Ross (1970) put forward the five stages of bereavement which she observed in patients who were told they had a terminal illness. However this process can also apply to chronic illness also as it is a loss and bereavement of one's old life and having to adjust and come to terms with a new life.

The five stages are Denial and isolation; Anger, Bargaining, Depression and Acceptance. The first stage, Denial and Isolation, is the initial reaction to awareness of a chronic or terminal illness. This stage is when a person does not acknowledge the weight of their diagnosis and the looming possibility of death. This stage of denial is said to be temporary and also a healthy way of dealing with the more difficult and painful feelings surrounding their situation, as it acts as a buffer to the shock and allows the patient to collect him/herself, and with time mobilise less radical defence mechanisms (Kubler-Ross, 1970). The initial experience of finding out one's status can be very overwhelming and denial counteracts this, but with partial acceptance then the need for denial is not as strong as it is initially. The second stage is Anger. Once the denial cannot be maintained any longer then feelings of anger, rage, envy and resentment towards God and or other people emerge, where the person asks him/herself questions like: "Why me"? (Kubler-Ross, 1970). This is usually a difficult time for the family as anger is displaced and projected into the environment and into them. The third stage is that of Bargaining. This stage is an attempt to postpone, it usually has to include a prize for good behaviour, it also sets a self

imposed deadline, and it includes an implicit promise that the patient will not ask for more if this one postponement is granted (Kubler-Ross, 1970). An example would be making a deal with God that if they are good then he grants them back their life. Kubler-Ross (1970) suggests that what is happening psychologically while a patient is bargaining and making promises may be associated with quiet guilt and it would therefore be helpful for others to acknowledge these remarks. This implies that it is important to offer these patients a listening space so they may be able to share their unconscious feelings of guilt and fears of punishment. The fourth stage is that of Depression. Once the patient can no longer deny their illness, when the numbness, anger and rage get replaced with a sense of great loss, then depression sets in (Kubler-Ross, 1970). The final and fifth stage is Acceptance. If the patient has had enough time and help in working through the previous stages then he or she will not harbour any anger nor depression but rather they are almost void of emotion about their fate (Kubler-Ross, 1970). In other words only once one has worked through and dealt with their difficult feelings around the tragic news can they begin to accept their situation and make meaning of what this means for their future. The time taken for the five stages to be processed is unique for each individual: they can follow one after the other or coincide (Kubler-Ross, 1970). These five stages show what people generally go through once confronted with traumatic news such as finding out their HIV positive status. These stages describe the defence mechanisms and coping strategies adopted in order to allow a person to process the trauma such as finding out ones HIV positive status. Kubler-Ross (1970) adds that the last thing that exists in all five of these stages is hope, in which one feels that all that they are experiencing has meaning. Part of this could be benefit finding where one finds positive meaning as to why they got the illness and engaging with benefits to their life now that they have been diagnosed such as living healthier and finding more meaning in life (Ridder, Geenen, Kuijer & Van Middendorp, 2008). Although Kubler-Ross' stages are helpful with regard to understanding the common experiences of individuals diagnosed with terminal illnesses, an HIV diagnosis is different, in that death is not imminent. For individuals diagnosed with HIV, they need to find a way to continue living after the stage of Acceptance. This needs to be borne in mind with regard to the experiences of the adolescents in this study.

Coping with a chronic illness like HIV as highlighted above can be quite a traumatic experience and defences are employed to cope with the difficult emotions evoked by such a trauma. Klein (as cited by Lemma, 2003) wrote that the ego identifies danger situations which gives rise to anxiety and therefore organises defences to protect itself. An HIV diagnosis can be viewed as such a danger, as death can be seen as quite real and imminent. The initial stages of finding out one's HIV status can provoke great anxiety and lead one to institute primitive defences to protect the ego. Living with HIV can provoke a fear of annihilation which for these individuals is a fear of dying. This kind of anxiety is said to be in the paranoid schizoid position, which is characterised by persecutory anxieties, where the individual is dominated by extreme fear that agencies outside the self want to harm them and this contributes to certain defences mechanisms (Klein, 1946). Contracting and living with HIV and the stigma that accompanies it can possibly evoke fears and anxieties of persecution. The defences deployed in the paranoid schizoid position are mechanisms of splitting internal and external objects, emotions and the ego (Klein, 1946). Coping with a chronic or terminal diagnosis can lead one to go into a paranoid schizoid way of functioning in which primitive defences, such as denial of inner and outer reality, stifling of emotions, splitting and projecting are also activated. One of the schizoid mechanisms is violent splitting off and destroying of one part of the personality under the pressure of anxiety and guilt (Klein, 1946). Another primitive schizoid defence mechanism that is used is projection which helps the ego overcome anxiety by forcefully evacuating danger, badness and unbearable feelings (Lemma, 2003). The anxieties of living with HIV can be traumatic enough to lead one to regress into the schizoid defence mechanisms, such as those of splitting and projecting as a means to cope with the anxiety and difficult emotions. Primitive defences have been discussed above; however, it is also important to acknowledge that neurotic defences can also be used as a way of coping with a chronic illness. Pedersen and Elklit (1995) found that in their study their participants relied more on neurotic defences than primitive defences, particularly in relation to anxiety. However they did find that primitive defences were positively associated with avoidance in the traumatisation scale. One could thus assume that depending on where one is in trying to process their illness will depend on what defences they employ to help them cope with the more difficult emotions and come to terms with their illness.

The process of living with a chronic illness is being able to come to terms with the illness; moving from a place of fear of death to a place of hope for a longer healthy life. An important part of acceptance of one's status and living a longer healthier life is adhering to ARVs. Ridder, Geenen, Kuijer and Van Middendorp's (2008) review indentified that there are at least five keys for adjustment to chronic illness. The first key they identified was successful performance of adaptive tasks such as an adjustment to disability, maintained emotional balance and preservation of healthy relationships (Ridder, Geenen, Kuijer & Van Middendorp, 2008). The second key identified was the absence of psychological disorders (Ridder, Geenen, Kuijer & Van Middendorp, 2008). As discussed earlier this must be carefully assessed for by clinicians as it can hinder the process of acceptance and being able to live a healthy balanced life. The third key was presence of low negative affect and high positive affect (Ridder, Geenen, Kuijer & Van Middendorp, 2008). The forth key is keeping an adequate functional status (Ridder, Geenen, Kuijer & Van Middendorp, 2008); with adolescents this would include being able to attend school and being able to function well at school. The fifth key was having satisfaction and wellbeing in various domains in one's life. Research shows the importance for clinician to have ongoing exploratory discussions with adolescents on their perceptions of the illness, how they cope with it and treatment, and how they could improve their adherence (Michaud, Surisa, Thomasa, Gnehmb, Cheseauxc & MoCHiV, 2010). There were also various models that were proposed for achieving these five key factors to adjustment and coming to terms with living with a chronic illness such as HIV. The modals included aspects of cognitive adaption which emphasises illness acceptance and perceptions of control over illness; ones personality such as optimism verses neuroticism; how one copes with stress and self-regulates such as how one deals with adaptive tasks imposed by the illness (Ridder, Geenen, Kuijer & Van Middendorp, 2008). These demands and changes have to happen on a cognitive, behavioural and emotional level for psychological adjustment, hope for a longer healthy life and coming to terms with living with HIV. A study on adolescence found that adequate psychological adjustment and effective coping mechanisms was linked with high adherence (Michaud, Surisa, Thomasa, Gnehmb, Cheseauxc & MoCHiV, 2010). Coming to terms with living with a chronic illness is a process that can take time as one has to adjust to the life changes however it is possible when one can recognise the

long term demands needed for adjustment and good adherence. This also indicates the importance of insight for adolescents adhering to ARVs and living with HIV.

3.5. Conclusion

This chapter aimed to provide a theoretical framework for this research. As this study is concerned with adolescents it was vital to provide a theoretical understanding of theories focused on the developmental stage of adolescence. As highlighted above, adolescence is quite a challenging developmental stage. An important part of the developmental process of adolescence is the process of identity formation; hence a brief overview of the process of identity formation was discussed. This chapter also discussed research that has looked at how HIV affects the process of identity formation. HIV seems to affect the process of identity formation in both a positive and a negative way. Living with HIV; a chronic illness and accepting and living with HIV can be challenging. Due to this, defences and strategies for coping with HIV are employed. Thus a theoretical understanding of defence mechanisms and coping mechanisms that are employed to cope with living with a chronic or terminal illness were also discussed. Within this scope, the five stages of the grief process (including Denial and isolation; Anger, Bargaining, Depression and Acceptance) were discussed and also ways in which one comes to terms with living with a chronic illness such as HIV.

Chapter 4: Methodology

4.1. Introduction

The chapter provides a full explanation of the methodology adopted during the research study. This includes detailed descriptions of the research design and the participants, the process of data collection, data analysis and the ethical considerations made when conducting the study.

4.2. Research Approach

The proposed research adopted a qualitative design. Qualitative research allows researchers to explore, describe and explain people's experiences, behaviours, interactions and social contexts (Fossey, Harvey, McDermott, & Davidson, 2002). The aim of this research was to explore the experiences of adolescents living with HIV and going through ART and therefore a qualitative approach was necessary as it allowed for interpretation of the participants' narratives around these topics, affording the opportunity to develop and understand the meanings and experiences of these individuals (Fossey et al., 2002). Through transcribed in-depth interviews that explored what they think and feel about having to take ARV medication, an understanding of the adolescents' perceptions and life experiences began to emerge. Analysis and interpretation of the interviews was conducted through the use of Braun and Clarke's (2006) thematic content analysis. This method of analysis allowed the researcher to gain thematic information on how the participants experience living with HIV, taking ARVs and adherence, through a process of outlining the major and more minor, but important themes that emerged from the transcribed interviews.

4.3. Participants

The participants consisted of 5 adolescents between the ages of 13 and 18 years living with HIV and on ART. The participants were recruited from a shelter for HIV positive women and children in Johannesburg, and participants were involved in the study on a voluntary basis. The shelter was chosen for the study as a number of HIV positive women and children live there, including a number of adolescents. However, after an initial meeting held by the researcher with the adolescents at the shelter, with the permission of the shelter's Therapy Director, it became

evident that a lot of the adolescents did not want to talk to the researcher or be part of the study. This was particularly evident amongst the females. They seemed to be quite uncomfortable with the idea of being involved in the study and this was evident in their disinterest in the study when initially introduced to them by the researcher. Their unwillingness to participate was confirmed through feedback from two of the caregivers, including the shelter manager, who are in charge of making sure that the children at the shelter are taking their ARVs. This study had a limited sample due to practical and time constraints and also due to the challenges experienced while recruiting adolescents to take part in the study. The interviews consisted of 3 male participants and 2 female participants. The following table describes the demographic characteristics of the participants. It also illustrates when their status was disclosed to them and also the age at which they started taking their ARVs. Pseudonyms have been used to protect the participants' true identities.

Participant	**Sex**	**Age**	**Status Disclosed to adolescent**	**Started ARVs**
Tebogo	Male	16	7 years old	Around age 6
Sipho	Male	17	5 years old	13 years old
Tshepo	Male	15	13 years old	Last year
Masego	Female	15	11-12 years old	11- 12 years old
Pule	Female	14	This Year	This year

Table 1: Participant Demographic Characteristics

This was a purposive sample which was chosen due to time constraints. As these participants are living in an institutionalised setting this may limit the generalisability of the findings to the broader population of HIV positive adolescents within the South African context, however the study generated in-depth data on these participants' experiences. The participants did not live with their mothers, as most have lost their mothers (to AIDS and some are from broken homes) and as a result are living at a shelter. So consent was obtained from the manager of the shelter

who is acting in 'loco parentis' for the adolescents. It was also a necessity that the participants sign an assent form themselves.

The aim of the research and permission to conduct the research at both the shelter's homes was obtained from the Therapy Director of the shelter. Once permission was attained, a meeting was set up to meet the shelter managers and adolescents at the shelters. At this meeting the researcher explained the aims of the research and the inclusion criteria of participants. The shelter managers at both the shelters homes were met first and the researcher explained the aims of the study and invited them to allow the adolescents living in their shelters to participate in the study. The researcher explained that she was looking to meet with HIV positive adolescents who are taking ARVs. Once permission was obtained from both the shelter managers at the shelters and it was ascertained that some of the adolescents living at the shelter are HIV positive and aware of their own and each others' positive statuses, the managers gathered the adolescents together. The researcher then met with the adolescents and an open invitation to participate in the study was offered to them. The researcher introduced herself and participants were informed that the researcher was conducting a research study on the experiences of HIV positive adolescents on ARVs. The adolescents were further informed that taking part in the study would mean they would be interviewed about their personal experience, understanding and feelings around being on ART and what adhering to treatment was like. They were also informed that the interviews would be audio recorded. It was also made clear that their agreeing to be a part of the research was voluntary and even if they decided to be a part the research they could pull out at any time. This information is further elaborated in the Participant Information Sheet in Appendix B. Participants were then informed that they could approach either the researcher or the residence manager at the shelters if they were interested in participating. The researcher availed herself at the shelter so that the adolescents could approach her directly if they preferred. This also allowed them the chance to come to the researcher privately if they had any questions regarding the study. The participants who were interested approached their shelter managers, who then contacted the researcher with the list. The researcher negotiated a time for the interviews with the shelter managers that would suit the participants. Upon the next visit at the shelters the researcher obtained the consent forms signed by the shelter managers acting in 'loco parentis'.

The assent forms signed by the participants were also obtained before the interviews commenced. The recruitment of participants commenced only once ethics approval for the study had been attained from the University of the Witwatersrand's Ethics Committee.

It is important to note that due to disinterest from a number of adolescents at the first shelter, the researcher had to also get permission to recruit more participants from the other shelter that formed part of the same organisation. They were included in the five interviews conducted. It was also then decided that the sample was sufficient as this was an exploratory study on these adolescents' experiences, which was evident as themes began to repeat in all the individuals' life experiences. The director put the researcher in contact with the shelter manager at the second shelter. The manager informed the adolescents fitting the criteria about the study and two participants whom were interested informed their shelter manager. The manager then informed the researcher who then set a time to come to the centre. The researcher then went to the second shelter to meet with the shelter manager and the potential participants. The research was thoroughly explained to the participants and both consent and assent forms were signed. The explanation and signing of the forms allowed a good opportunity to build some rapport with the participants and answer any questions and concerns they had. The assent forms (both for participation and permission to audio-record) were signed before the interviews commenced.

4.4. Data Collection

After the recruitment process and signing of the assent and consent forms was completed; five semi-structured, in-depth interviews were conducted and a voice recorder was used to record the interviews. This interview style allowed the researcher to be able to open up the interview in order to elicit the aspects of the adolescents' experiences that were most pertinent to them and then to focus the interview more specifically on the adolescents' experiences and understandings of ART adherence instead of getting too broad a story. The focusing of the interview occurred through the use of a pre-designed interview schedule. The questions were constructed focusing on particular themes that hoped to elicit the participants personal experience, understanding and feelings around being on ART and adhering. The themes that were explored were around the participant's experiences of disclosure of their status by their guardians or parents; experience of

disclosure to others; disclosure of why they are taking ARVs; experience of taking ARVs, what they think and how they feel about this; and adherence and identity issues related to living with HIV. These themes were informed by the literature that was read on this related topic. The themes are further illustrated in the interview schedule which can be found in Appendix H. The semi-structured interview design was suitable for obtaining in-depth information and it does not restrict the interviewer to a prescribed interview schedule, yet gives the interviewer the opportunity to ask the same questions to all the participants (Sommer & Sommer, 1997). A semi-structured interview was appropriate for this study as it allowed for a more focused exploration of a specific topic (Fossey et al., 2002). This also allowed the researcher to be aware of non verbal cues which was valuable for interpreting the participants' feelings towards certain questions and around the various responses they gave.

The five Individual interviews were conducted privately in offices provided by the shelter managers. The interviews were 45 minutes to an hour long and were mostly conducted in English, as all the adolescents at the shelter attend English-medium high schools. However there were moments within the interviews where questions had to be translated into the participants' various home languages and the adolescents also sometimes responded in their various home languages. The researcher was able to translate questions and answers when needed into the vernacular language which was known by the researcher. A translator was not needed in this research as the participants were for the most part fluent in English and the interviewer could speak a few African languages. These interviews were face to face, which provided an excellent opportunity to explore the feelings and attitudes that the participants have towards ART and adherence, which, as the interviews progressed, the participants felt comfortable enough to express. Face to face interviews also allowed the researcher an opportunity to observe other valuable factors: such as general appearance, overall health, personality, non-verbal behaviour and other individual traits (Sommer & Sommer, 1997). Audi-recording the interviews allowed for the researcher to concentrate and pay full attention to the interviews and learn about the participants and their life experiences, without having to take detailed notes. Immediately after each individual interview was complete the researcher made detailed notes of her observations

during the interviews, such as how participants responded and reacted to the questions asked and themes explored.

4.5. Data analysis

The recorded data between the researcher and participant (adolescent) was transcribed to attain the data content. The transcribed data was anonymised to protect the identity of the participants. A thematic content analysis was used to analyse the data. The thematic content analysis permitted the researcher to indentify, analyse and report patterns (themes) within the data that was obtained from the adolescents (Braun & Clarke, 2006). Using this approach helped to describe the data in detail and also allowed for exploration of the various aspects of the research topic (Braun & Clarke, 2006). It was important for the researcher to be flexible especially when analysing the data and establishing what should count as a theme and what should not. The researcher was flexible in the sense that she was able to allocate sections of the data to different themes when they were better described by a different theme and also in the changing around and, or re-naming of themes if they did not quite capture the findings. The aim of this research was to provide a rich thematic description of the entire data. The thematic content analysis that was conducted outlined the major and minor, but important themes that emerged from the data (Braun & Clarke, 2006). Inductive analysis allowed for themes to be identified which were not prescribed by the researcher's theoretical interest but rather determined by the transcribed data. This was done through analysing the transcribed interviews and analysing the meaning of each quote and working out what the participant was communicating to the researcher. This approach allowed for rich descriptions of the data obtained, which are presented in the chapter outlining the results of the study. The data analysis method utilised in this study followed Braun and Clarke's (2006) six phases of thematic analysis, which were: becoming familiar with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the research report. The researcher transcribed most of the interviews and the rest of the interviews were transcribed by an independent transcriber. The independent transcriber signed a confidentiality clause that she would not disclose any of the information in the interviews. Once all the interviews were transcribed the researcher read through the transcriptions to generate the initial codes. This was done by using different coloured pens to

colour code the various themes which emerged. The initial themes which were generated were understanding and awareness of HIV status, process of acceptance, not knowing and the need to know how they were infected with HIV, identity issues (being different and belonging), fear of what others will think, need to keep secrets, death and life, bad medication, bad hospital, non-adherence (defaulting), good medication, good hospital, trusted other and defences to manage. These categories/ sub-themes were generated through an interpretation of what the participants were communicating in each of their quotes. Once this was completed, the researcher grouped the various sub-themes under more overarching themes into a Word Document and then re-read the interview transcriptions, copying and pasting the various quotes into the respective themes generated in the analysis. The overarching themes were understanding, bad medication experiences, challenges and facilitators. Some of the quotes in the various sub-themes needed to be shuffled around to more appropriate themes. Once this stage was completed some of the themes were renamed to better capture the themes elicited by the participants' shared experiences. The overarching themes were edited to the following categories: Relationship to the ARVS (consisting of the sub-themes: understandings of the medication; 'Bad' meds,'bad' hospital and defaulting; and Help (good meds and trusted others)); Integration of ARVS into their identities (consisting of the sub-themes: experienced identities; not knowing and needing to know how they got HIV; secrets and fear of rejection; challenges; life and death; and defences) and the last predominant theme was the Process of acceptance. These themes are further elaborated in chapter 5 of this research document. In the discussion found in chapter 6 there were some further adaptions made with different groupings and renaming of sub-themes which provided a better understanding and structural flow of the information provided by the participants on their experiences of living with HIV and adhering to ARVs. The following main headings in the discussion complemented the research questions and included: HIV positive adolescents' experiences with ART adherence (consisting of the sub-themes: the importance of disclosure; the struggle to develop an identity and choosing to live); The challenges adolescents experience in adhering to their ARV medication (consisting of the sub-themes: the inconvenience of ARVs; the stigma and fear of ARVs; depression and loss and ARVs; and ARVs complicating normal adolescent developmental challenges); and the last heading was The factors that help adolescents adhere to their antiretroviral (ARV) medication (consisting of the

sub-themes: understanding and awareness; support; practical strategies; emotional defence mechanisms; and the process of acceptance).

4.6. Ethics

Ethical considerations are paramount in all research. The participants in this research study were a vulnerable group and the research was sensitive to this fact. Therefore a number of steps were followed in order to ensure that the rights of participants' were protected. The first step was to obtain permission from the Director of the shelter to conduct the research at their centre, which was attained. Ethical clearance for the study was also obtained from the Ethics Committee at the University of Witwatersrand (ethics clearance number: H1 10224). Once the list of participants was generated, the managers from both the homes forming part of the shelter, who are the guardians at the shelter, were met for the researcher to explain the aims of the study and invite them to allow their adolescents to participate in the study. After thorough explanation of the study and what participation would entail was provided for those interested in participating in the study, informed consent from the guardians and informed assent from the adolescents was obtained.

In order to ensure confidentiality all names have been changed and the name of the shelter has been omitted from the final report. All participants were offered full confidentiality at all stages of the research project, with the exception of a self-harm clause. Due to the high risks linked to non-adherence on ARV medication, it was decided that if during the interview it came to light that any adolescent was not adhering to their medication, steps would have to be taken to ensure that this was addressed. It was decided that if a participant shares that they are not taking their medication that there would have to be a debriefing session where the researcher would discuss the concerns that came up and the need to tell a caretaker at the centre or the adolescent's guardian. Before each interview the participants were informed that if they disclose that they are currently harming themselves or intend to harm themselves, that the researcher would be obliged to break confidentiality in order to access help or assistance for them. However, participants were informed that if this situation arose, that this would be discussed with them and then they would be given the opportunity to choose the person at the shelter they would like the researcher

to tell, so that the adolescent's safety could be ensured. When issues arose this was discussed with the participants to ensure whether they were getting counselling and free counselling was suggested to them where the participants could get further assistance and support. With the agreement of the participants, the researcher also spoke to the shelter manager who was aware of the adherence problems and who told the researcher about the ways in which they attempt to manage these issues and difficulties experienced by the participants.

It was explained to both the adolescents and their guardians that participation in the study is voluntary and if at any point they wanted to drop out of the study they would be free to do so without any consequences. All the participants' identifying information was removed from the transcripts and the research report and pseudonyms were used.

Participants were informed that the recordings and the transcripts of their interviews would be kept securely locked by password on the researcher's computer for 2 years if the research is published in a journal, or kept for 6 years if it is not published, before it can be destroyed. They were also informed that if they wished to see the results of the study, that general feedback would be given in the form of a letter to the participants. However the participants did not request feedback. The participants were also informed that the Director of the shelter would also receive a letter summarising the findings of the study. It was also made clear to all the participants and their guardians that the finished report and any articles generated from it would be seen by the public.

Chapter 5: Research Findings

5.1. Introduction

A thematic content analysis was conducted in order to discover themes that might provide an overview of the adolescents' experiences. The following chapter will discuss the results of this study in relation to three predominant themes which were identified as: the adolescents' relationship to the ARVs; the integration of ARVs into identity; and the process of acceptance. Although these three predominant themes are written about separately in this section, many of the subthemes are interrelated and certain subthemes may appear throughout the chapter. This chapter will also include the researchers self reflection of doing this study.

5.2. Relationship to the ARVS:

A large part of the interviews explored the adolescents' feelings towards their medication, how they understand the medication and the purpose of the medication. What arose from the interviews was a love-hate relationship with their medication which has been discussed under the following sub-themes: 'Bad' medication, Defaulting, 'Bad' hospital and Help ('good' meds and trusted others).

5.2.1. Understandings of the medication

Understanding and awareness seems to have played an important role in how the participants began to acknowledge their HIV positive statuses. Many described a process in which they began trying to make sense of this for themselves. The disclosure of their status was generally followed by an awareness of why they need to take their ARVs. Many of the participants shared how they had managed to make sense of this and apply this new understanding and awareness to their daily lives. Tebogo explained that finding out about his HIV positive status came with the realisation that he will be living with the illness all his life:

> I learnt my HIV status and stuff, ah begin to learn about it more, it was in 2002 or 1. That's when I got aware that actually I'm HIV positive, why I'm taking this medication right now... First time I thought ah, it was nothing. It was like those other diseases like

> flu and stuff and stuff but when I learnt more about it, found out that I'm going to live with it for the rest of my life.

Tebogo also spoke about how at first he had thought that his ARVs were the same as the sweet medication (most likely vitamins) that he had to take when he was younger but then he became aware and realised that these tablets were different, and learnt that they were ARVs. He said: "Yes, cause I was like, I thought that like, cause over here they use like give us ah, tab, those sweet tablets to drink, so I thought that it was the same stuff but in a familiar way, so like... like, like in other way, like they not the same colour stuff and taste and stuff".

Many of the participants stated that they had felt an array of strong feelings upon finding out about their HIV positive status. Tshepo described feeling shocked and surprised, while Sipho describes initially thinking that his sister was joking with him, but becoming really sad when he realised that she was telling the truth:

> Eh, I wasn't thinking that is a serious thing... Yes, my sister told me, I take it, as ah, they are playing ... I was feeling so sad, because my sister explained to me that what is HIV positive ... My sister told me that I've got something in my body. The thing that I have, I found it in my mother's breast. Eh before my mother passed away, I found it through my mother's breast.

Pule described a sense of disbelief upon being told about her status by a nurse: "Yes but the other time was sleeping there at my bed at hospital, the other sister she's talking she say do you know how is your sickness is for what? I say that I don't know, I started thinking if she just kept quiet... It's for what, yes I didn't think about can be HIV positive". Thus, disclosure of their being HIV positive evoked different reactions, such as surprise, disbelief and even feelings of sadness. This was also a process for them of trying to figure out what it means to be HIV positive through the understanding of their status. Some of the participants were already on ARVs when they were told about their status, but describe not having had an awareness as to why they were taking ARVs and what the purpose of these were. Not having an awareness as to why she was taking the tablets led to Masego wondering when she could stop taking the medication. She stated: "I was, I was just thinking about when am I going to finish my ARVS, I just thought that I can't, I don't feel like drinking this anymore than before". Pule, when asked about what she thought the purpose of the ARVs was, explained that initially she had not known this, but had

been told: “I didn’t understand it. Yes. See actually they told me if not taking it then you can die...” It appeared that for most of these adolescents, their first experiences of taking ARVs occurred without a full understanding or acknowledgement as to why they were taking them. However it seemed that with time they began to understand and contemplate more about what it meant for them to be on ARVs and they also became aware of the issue of adherence or what they referred to as ‘defaulting’. Tebogo explained his understanding of the importance of adherence:

> You do make a mistake it’s alright, it’s alright but before 4 hours you must have drink your medication... They won’t work cause if work after four hours, you got to wait cause you got to still drink at night, it won’t go by six- six, it will go by that time... Nah, if you miss the 4 hours you have to wait for that night, that evening four hours... Then you have missed out, like you didn’t drink anything... Mmm, defaulting... Um, my guardians he told me, they, they usually know much about my medications.

Sipho also explained how he was taught the importance of taking the right medication in the right order: “Eh. She say that I’m jumping my pills; I’m not taking them in order... If I don’t take them in order, they tell me that I must take them in order...They was teaching me step by step so that I must understand”. Tebogo also shared how he learnt from another child the importance of also eating well so you do not get sick. He said:

> Like okay, I use, I use to wonder like, when ever like us we’re sick with like flu and stuff. You might be sick, for the, for the next three days, okay come back. But like she was always, she was always, she was always healthy. She ate fruits and stuff so I was like wondering, ain’t that, ain’t that pos, ain’t that possible okay. It is possible if, you can take fruits and if you live in a rich family and stuff if you eat well there’s food and stuff and stuff.

Being told about their HIV status, understanding what it means to be HIV positive, understanding the reasons they are taking ARVs, and how to keep healthy and the importance of this, all appear to be factors that have allowed them to begin to process what it means for their lives to be infected with HIV, what it means to be on ARVs and the importance of adherence or what the adolescents referred to as ‘not defaulting’.

5.2.2. 'Bad' meds, 'bad' hospital and defaulting

A number of factors were highlighted by the participants which appeared to play a role in some of their negative experiences around taking ARVs and how some of these factors may result in them or their friends not adhering to their medication. Tebogo described how frustrating it is for him to wake up every day to take his ARVs and also how much he hates the taste of his medication:

> Sometimes it is annoying because you have to wake up early in the morning, that's what I hate waking up early. I don't like waking up and if you don't up early in the morning they come and drag you up, wake up, wake up... My meds ah, my medication, yah they pretty much ugly when they taste through. When they come pass the tongue when u swallow them or get stuck over here (touching throat) argh, on your throat, tasteless and stuff...I once told my doctor that this medication are not good cause when I drink them I often want, also want to take them out , vomit or something... That's an everyday thing like sometimes when I drink them I ask myself ah, I don't want to continue my life but, yah, yah, yah, so disgusting but I have to drink them in order to live. So I have no choice.

While Tebogo's dislike of his medication seemed to be linked to the side effect of nausea that he experienced, his comment also suggested that his wish to 'vomit' the medication out may be linked to a wish to not have to take them or perhaps a wish to 'vomit' out his HIV. Sipho also shared his bad experience of taking his ARVs such as the negative side effects when he first started his ARVs:

> Ah, I was getting sick the time I was starting to take them, and I grow up, I grow up. They told me this is the pills that you have to drink them until you die... They find that the medication that I was taking them first, they are not ok to me. After I sleep, they say, we are going to, you are going to here, we are going to find another medication those you can take them until you get okay.

In addition to unpleasant side-effects, the inconvenience of the medication was also cited as a reason that the medication was 'bad'. While Tebogo did not enjoy having to wake up early to take his ARVs, Tshepo expressed how angry he gets when he is enjoying doing something and he has to go take his medication. He shared that sometimes he gets so angry that he contemplates defaulting:

> It's like when I get angry, when they say "medication time", maybe I'm watching something interesting, then I got their attention, when they say angry medication, I just stop, my mind can go backwards, feel like I can take the time back, then I get angry, pissed- off, I feel like I can say "stuff medication... then I just take them, but not happy inside, you know in the outside it can show that ah, probably this guy is not happy, damn he's so angry.

Masego shared how tired she gets because it feels like it never stops; that she has to keep on taking her medication. She also felt that this frustration sometimes contributed towards her not wanting to take her ARVs:

> I went to the sick bay then I was like when are these pills getting finished then their like when you are older but since I was young I was drinking them how can they finish when I'm older? Then they are like there's nothing you can do Masego you have to drink them. Then I'm like no I'm tired, I'm tired, I'm tired then like, Ah.

Taking medication seemed to be a major challenge and from the extracts above it seemed that the taste of the medication made it difficult to get used to the medication. Some of the participants experienced severe side effects from their ARV regimes which resulted in hospitalisation and a need to change the regime. ARVs were also represented as a burden in the sense that there is a specific time in which they have to be taken and sometimes this disturbs sleep and other activities, which many of the adolescents found quite frustrating. Adding to this frustration was the knowledge that they have to continue to take their medication for the rest of their lives, which is a burden for them.

Along with the challenges of the actual medication there were also some challenges experienced in relation to their health care providers. Sipho stated that he does not like going to the hospital as he worries people will know he is HIV positive and he finds the process too long. He also feels sad when he is found out for not adhering to his ARVs which leads to a lecture of what not taking his ARVs could result in:

> I feel like, like I can get out of there and go back home... Because I see many people, I think that they are gonna know that I got HIV... I go to the hospital; I started to

> Counsellors, after Counsellors, I go to the Doctor, Doctor check, after Doctor, I'm going to the Chemist, after Chemist I'm going home... If I getting there, they take my containers they count them, if I don't drink ok, they told me "why are you not drinking ok, your medication?"; after they tell me if you not drinking your medication ok, you going to die... I'm getting, feel, I'm feeling so sad.

Tshepo's following statement seemed to reflect a process that would be overwhelming for anyone, let alone an adolescent. He seemed to become confused by the amount of information he is given at the hospital: "there is like it's cool, but sometimes they can explain too many things, they like 'take this 2 times a day, take this' they are doing it fast and like some people don't understand them, and they will just do their own things". He seemed to feel that the sense of being overwhelmed also contributed to defaulting on medication. Masego spoke about hating having to miss school for her hospital checkups as she feels due to this she falls behind at school:

> Sometimes I just go during the week when I have to go to school then I just get angry mmm... I get angry cause I have to write something then I just ask them why today, then they like it's your day. Then like you have to tell my teacher. Then they like okay I'll tell the teachers. Okay cool ... Sometimes it's boring and it's quite obviously... I just get bored.

The above extracts illustrated some of the negative experiences that the participants have experienced at the hospital. A number of issues were highlighted, including: people discovering they are HIV positive, which is linked to a fear of rejection; going to the hospital for checkups which results in them missing school and concerns around falling behind at school; and that going for checkups is a tedious process that is sometimes overwhelming. It also seemed that sometimes the information they were given felt too much to take in and was difficult to understand. At times, these bad experiences of taking medication seemed to strongly influence the participants and their friends, resulting, at times, in defaulting on their medication, as will be seen below.

Sipho also spoke about how sometimes the pain of missing his mother gets so much that he does not feel like taking his medication, so he defaults:

> Eh sometimes if I'm not taking them, if I don't like to take them, I'm making like I'm sleeping, and I'm not sleeping, after they wake up me, I, I lied about I'm having a headache. They bring them to me, after bring them to me I don't drink them, I throw them away... Coz I was feeling, I was think about my mother all the time, and this thing is not getting out of my heart... Another friend that has HIV asked me, "Sipho, why are you not going to drink your medication?" I say, I lied, I say I already drink them lot of time.

This seemed to suggest that the adolescents' moods influence adherence to their medication; when depressed or preoccupied with worry, the motivation to take their ARVs seemed to decrease. Tshepo expressed how sometimes he just gets so sickened by taking his ARVs that he defaults. This statement also expressed his ambivalence around whether to take his ARVs or not and how sometimes he chooses not to take them:

> I like don't wanna take them, you feel so disgusted when they say medication...for me, sometimes, I feel like, it says just run away or hide them under the bed because they won't, and like, sometimes I want to but I just can't. I need to take my medication... like I was feeling lazy to take them, so lazy because like I came back from a soccer practice, soccer practice; and they say, uhmm "come and take your medication nani nan." I told them that uhm, like I'll come back in 2 minutes, they say ok, then I just went, I didn't come back and I'll, like, I was sick that my eyes were red, lazy again, I don't want food and stuff.

It seemed that Tshepo being sickened by his medication may have been about his anger and hate towards being HIV positive and having to take medication and a wish to escape this, but realising that he cannot as there are consequences to this. Masego shared her observation of why and how some of her peers go about defaulting. In this quote she implied that some of her peers feel like having HIV is overwhelming and they don't want to engage with this. They need to avoid thinking about it and avoid anything that reminds them of it. This appeared to concern her, as for her taking ARVs means choosing life and she was afraid to lose her friends and was perhaps afraid of her own anger and resentment at having to take the pills:

> Like, it's like um, they don't want to take them anymore and some of them they do throw their medication and flush them or in the dustbin that's why... Cause they don't want to drink them, they like some of them they're tired to drink their medication, that's why they throw them away... I just feel like I, I ask myself why do they throw them cause like

> it's their life, they don't know what's going to happen tomorrow and I ask them why do you throw your medication, she like. No I don't want to drink them anymore. Then was like there is nothing you can do, you have to, you have to. Then she's like I don't drink, I don't want them anymore.

All the participants were quite open about how sometimes they do contemplate defaulting and though some shared that often they do end up taking their medication despite not wanting to, some admitted that, at times, they do not take their ARVs and when asked by their caregivers, they lie about it. Some of the participants even shared that they are aware of some of their peers at the home who do not adhere to their medication, and how they lie about taking medication, and throw their medication away. There did however appear to be consequences to them defaulting, which the participants also openly shared. Sipho shared the trouble he gets into when his sister discovers that he has been defaulting. He said: "My sister, if I'm not drinking my tablets, sometimes she shout at me or beating me". Tshepo spoke about the health consequence of not taking his medication and how this worries him which then leads him to taking his ARVs. He described how he feels if he hasn't taken his ARVs for a while:

> I'm like exhausted, tired… like everything, and I'll just want to sleep, and sleep, and just don't do anything, just sleeping... sometime like it worries me I didn't take them, I'd say, like at the night what if tomorrow I wake up dead or something from this medication, and I'm like, like ok pissed… and they when I didn't take them about for 2 weeks, on maybe, Monday then I take them, I get my body back and I get that energy and then, yes ... for the first week, things were perfect, the second week things weren't perfect...like I don't want to eat anything.

As illustrated above, some of the consequences of the participants not adhering included getting into trouble from their caregivers when it is discovered that they have been defaulting. The other consequences are those of a physical nature, such as their heath declining and major concerns of dying due to not taking their ARVs.

5.2.3. Help (good meds and trusted others)

Understanding what their ARVs are for and how they can help seemed to be very significant to these adolescents' meaning making processes. This awareness seemed to enable them to overcome the challenges they face with taking ARVs and in adhering to their ARVs. The

participants also noticed and identified the positive changes in their health since starting to take their ARVs, which seemed to facilitate the process of acceptance and adherence to their medication. It also seemed that having a good relationship with their doctors and a positive experience at the hospital also encouraged them to adhere to their ARVs. Tebogo expressed how important taking ARVs is for him as they keep him healthy, alive and away from hospital, and that they allow him to focus on attaining his goals:

> Okay, ah, taking medication, taking my meds is a big role in my life, cause without that medicine I'd me like okay, suffering and stuff in the hospitals, yah fighting for my life... What I understand is that they help you, they help you reach your goals, reach anywhere you want to be, because without life there is nothing. If you, instead, okay let me make an example: If they said okay, there is no more life in this world, there would be nothing, but my plans in the future is like is about curing AIDS and stuff so that's why I'm benefitting from doing and working hard and providing what I want in the future and doing stuff.

Tebogo's statement seemed to reflect a fantasy of being able to cure HIV and it seemed that the medication is linked in his mind to a sense of hope for the future. Sipho also felt that ARVs keep him alive and that they are his only hope for life: "I feel ok because they are saving my life... Ah medication… I take it as my life... Without it ah… nothing else is going for me, to going to make me alive, without medication". Masego also expressed how ARVs have increased her life span so she can spend more time with her family and friends. She said: "Because I just want to live longer with my family and other people, that I actually know, even here, like that even when I am angry, but I do talk to them and sit with them". Thus the meaning attributed to their ARVs was that it gives them a life, a future to be with their family and the opportunity to reach their goals. This hope for a future seemed to motivate them to take their ARVs. Tshepo shared how when he bumped into his old friend who is also HIV positive he realised how ARVs had helped him, which motivated him to take his ARVs and grow like his friend had:

> There's a boy I used to go with, what's his name, is it N? We went there I think in 1999. He was born January, I was born July, and then he was like HIV, we were like so short then, we just grow up together and now he is fat and I'm like, "wow you have grown", then he'll tell me 'you are taller; you are even taller than me'. Then I get motivated, like

> he's like medication can help, ne bra? And I'm like, yes it can, just taking them and growing day by day.

Masego also shared how her ARVs have helped her to gain weight, have more energy and improved her health: "I just feel like... I just feel like I now, I'm now; I'm now picking up weight and all the stuff. I'm just feeling okay about them... They are building my body and like even when I'm sick I'm just drinking them. Then I just get some more energy than before then I just get better". Pule expressed how now, due to her ARVs, she is healthier and does not miss school as she did before: "For me what is easy, because it helps me every time. Yes I was thin, they...I'm getting better now. Yes... Because I'm I can go now to school I'm not sick". The above quotes illustrated how the participants see their medication improving their health, their physical appearance and how people can notice the change in them. Their health improving and them not getting as sick as they used to seemed to mean that other areas of their lives also improved, such as not being sick all the time and not being absent from school as much.

Having a good relationship with their doctor also seemed to be a contributing factor to a positive experience with taking ARVs. Tebogo described how he feels close to his doctor and that he is able to be open with his doctor, which facilitated a good working alliance and him adhering to his ARVs:

> Yah she is always telling me I must feel free to ask anything. That's why, that's why I'm always closer to her and stuff. I ask her things, okay, can you do this for me can you do this for me okay, she also asks can you meet me where, where, where and bring our files and stuff. Yes I'll bring them... She often like asks me something, okay, I'll do it and I'll ask her and she'll do it, like that.

Tebogo seemed to be expressing how important it is to have someone trustworthy like his doctor, with whom he can be open and who is genuinely interested in his well being, which seemed to really motivate him to do what he says he will do. Tebogo also spoke about enjoying going to the hospital, as there is a support group with his peers that share and understand his experience, to whom he can talk and have fun with: "I found out there a group of children, a group of my age group talking about this; always having fun, nice things, always having fun, eating, having fun, drinking stuff. Mmm, doing activities, doing soccer". Pule also expressed how she is encouraged

by going to the hospital as she is able to be with other children who are going through the same experience that she is. She also relayed having a positive relationship with her doctor that encourages her: “It’s like everyone is taking it just like me. Yes... It makes me feel better because I saw lots of people taking, fetch their ARVs. That’s why it make me better...It’s good because she’s always telling me that I’m going to be fine, yes. I must take my tablets all the time”. This quote reflected a sense that the doctor plays an important reassuring role. It seemed that having a doctor whom she trusts to tell her that she was going to be alright, allowed her to believe this could be true and then her anxiety could decrease. Thus, for these adolescents, a positive experience at the hospital seemed to facilitate a more positive experience around taking their ARVs. It also seemed that a good quality relationship with their doctor also helped because they were able to communicate with their doctors around their challenges and the doctor was able to advise and encourage them. There was also a sense that at the hospital they were able to meet their peers who are also taking ARVs and they seemed to experience a sense of comfort and hope in being able to relate to others in a similar position.

Trusted others

There were various ways in which the participants managed taking their medication, both at a personal level and also at a relational level. What came through strongly was the need for people whom they can trust and rely on to help to remind them to take their medication, who make sure that they have taken their medication and also protect them from getting infections as their immune systems are sensitive. Sipho described how pleased he is to have someone to care for him and makes sure he adheres to his ARVs:

> Ok, I’m getting happy because I got, I get, there’s a sister that is take care of me. She check every day that I am drinking my tablets... Sis B take care of me, take care of me every day, to drink my tablets every day... Eh they called, they call me before 6, they call me that “Sipho you did not take your medication. Go and drink your medication”... They sit with us; they see that we are drinking our medication right or wrong. If you are drinking wrong, they teach you that, no you are drinking wrong your medication, you have to drink your medication, like this, like this, like this.

Tshepo expressed how he trusts the adults who help him take his ARVs: “Obviously they are adults, I trust them and they... Sis B gives us medication every day, and Mam’ Z makes sure,

makes sure that I get that medicine". Masego also expressed how safe she feels, as the sisters at the home take care of and make sure she takes her ARVs properly and does not get sick:

> I'm okay with them. They're kind and they're responsible for me and others... Because they help me and they protect me from some diseases... Like, if like, isn't it in sickbay there's people who are sick, some of them they stay in the other room and so if I come and take my medication, I just go in the sitting room and drink there then I come out again. They don't want that I must get infection from others... They waking, they are waking me every day at 6 o'clock.

The above extracts illustrated how for most of the participants it is important for them to have someone whom they trust to remind them to take their medication, who makes sure that they take their medication, and who protects them from harm, such as keeping them from getting infections. The participants expressed how these trusted others are also able to explain and advise them on how to take their medication. Having these helpful and supportive caregivers seemed to make it easier for the participants to manage taking their ARVs, which helped to give them a good experience of taking their ARVs.

As the participants live in a home with other adolescents who, like them, are also taking ARVs they tend to help each other. Pule spoke about how she goes with Masego and another child to go get their medication. Tebogo shared how in his room there are others who take ARVs so they wake each other up in the morning, which helps:

> Okay, we like, like, we boys in our room and stuff, some of them, okay, okay, some the children medication, down there, neh, we like, we know each other, okay, we drink medication, the same medication and stuff, so when he wakes up, he also wakes others, we wake each other up, when we late, if I wake up early, I wake each other, each and everyone up who takes medication, then we all go and drink.

It seemed evident that they help each other and that when it is time to drink their medication they are able to remind each other and go and get their medication together. This supportive environment seemed to help as then they do not feel so alone. Feeling alone was a common experience for them, however, this will be discussed later in this chapter.

Most of the participants seemed to get a lot of support and assistance with taking their ARVs, however, they were also able to employ different ways in which to take responsibility themselves and manage taking medication on their own. Masego shared using her phone alarm to remind her when there is no one around to remind her. Tshepo spoke about how he pays attention to the time when he is at home so that he does not miss his medication time: "Like when I'm at home, I just look at the watch, at 6 I drink the medication, then I carry on with what I was doing, because like if I skip, night one, ah maybe I will default, then that's a big problem... because of my status, and my... like uhm, like, HIV, I need to make sure that I don't get AIDS". Paying attention to the time or even using their phones to set their medication times illustrated them taking control and being responsible for their ARVs when their trusted others were not there.

5.3. Integration of ARVS into their identities:

The next predominant theme that the analysis highlighted was that of integrating ARVs into their identities which included the following sub-themes: Experienced identities; Not knowing and needing to know how they got HIV; Secrets and fear of rejection; Challenges; Life and death, and Defences. This section looks at how the participants adjusted their self concepts, particularly in relation to their HIV status and taking ARVs. Issues of being different from their HIV negative peers and fear of rejection were highlighted and thus they live a life full of secrets. This section also looks at the challenges they face and strong sub-themes emerged with regard to HIV and ARVs being associated with life or death, and the various defences the adolescents employed to manage these challenges.

5.3.1. Experienced identities

Another important area that was influenced by the participants learning about their HIV status and understanding why they have to take ARVs is how they perceive themselves, particularly in relation to their peers and also how their peers see them, both those peers who are HIV positive and those who are HIV negative. Tebogo shared his concern and anxieties around being the only one at camp taking ARVs and his relief when he discovered more children like him who were taking ARVs: "Last year, it was pretty much hard because I thought I might be the only one in that group who did drink medication, but others came out". Tebogo explained how at school he

had thought he was the only one who was HIV positive and expressed his delight to find out that he was not and wanting him and this girl to stick together as he felt a sense of belonging as they had a shared experience:

> But when I saw her coming with it, I was like, was like, I thought I was the only one and I was like, I went to her nicely, I asked, I didn't like, I didn't like jump to that topic are you HIV positive and stuff cause obviously she was gonna freak out and go tell her parents and stuff. So I just pulled her to the side okay I said okay, like those pills are the same as I, are the same as my medication, she's like how, I took them out, she says how, you also on the treatment that I have. That's when I started the topic, okay maybe we both HIV positive mmm, I'm also HIV positive, okay, let's stick together, cause we the only two in the class, let's keep this a secret okay, sharp.

Sipho expressed how sometimes he does not feel like he is the same as his HIV negative peers, as he is not as healthy or physically fit as them which saddens him: "Sometimes I feel them, I'm one of them, those who are not taking the medication, sometimes I'm thinking, I'm thinking that this thing I'm thinking of ah, it's wrong... eh if I'm playing with them I'm getting tired faster. If I'm not playing, I get flu, just like not, it's hot or not, I get flu just like that... It feel bad". Tshepo on the other hand felt that besides being HIV positive, he is not different to his HIV negative peers: "Other teenagers, my life and their life it's the same, the difference is just that I have HIV but no one can see, they can hear it, not see it". In the following extract Masego communicated her ambivalence around how she views herself in relation to her peers, as sometimes she does view herself as different from her HIV negative peers and sometimes she feels like they are no different: "I'm just ah fine like it's not um rough for me cause some the teenagers they don't have it and it's only me and X that have yah ... Sometimes I do feel like different and sometimes I do feel like... me". Pule expressed how painful it is to be sick, missing school and having to take medication when the other children do not have to:

> What's hard; is you see your friends she doesn't take them... only you take them and then your heart gets sore. Yes... Um, when I see my friends are not drinking and just sit there, me always I always, I getting... It has been sooo sore, yes. Because when you see your friends they don't take tablets, yes... And I'm not going to school the other ones go to school, me I'm always sick.

In the extracts above it was suggested that for most of the participants there was a strong sense that they are different from their HIV negative peers and how emotionally difficult this can be for them. It seemed that there is a fear that they are the only ones taking ARVs; they feel they are not as fit as their HIV negative peers, and it is difficult to have to be the only ones having to take medication. Most of them explained feeling that their HIV negative peers do not have the same concerns that they have, like their health and having to worry about their ARVs. The issue of stigma and shame around having HIV also emerged strongly. Tshepo expressed that there was not much of a difference besides the fact that his peers are HIV negative. He seems to be able to identify more with his HIV negative peers and feels that there are more similarities than differences. Masego also did not seem to find it very difficult being different, though she mentioned that sometimes she does feel that she is different.

On the more positive side another theme that emerged was a feeling of belonging with other adolescents who are HIV positive which is further highlighted below. Tebogo explained how at school he had thought he was the only one who was HIV positive and was delighted to find out that one of the girls in is class was also HIV positive. He expressed having wanted them to stick together as he felt a sense of belonging with her due to their shared experience:

> But when I saw her coming with it, I was like, was like, I thought I was the only one and I was like, I went to her nicely, I asked, I didn't like, I didn't like jump to that topic are you HIV positive and stuff cause obviously she was gonna freak out and go tell her parents and stuff. So I just pulled her to the side okay I said okay, like those pills are the same as I, are the same as my medication, she's like how, I took them out, she says how, you also on the treatment that I have. That's when I started the topic, okay maybe we both HIV positive mmm, I'm also HIV positive, okay, let's stick together, cause we the only two in the class, let's keep this a secret okay, sharp.

Tshepo expressed how at the shelter where they live there are other children like him who are taking ARVs, so he does not feel like he is alone but rather feels a sense of belonging which helps: "Ah I feel like, ok, it's not, uhm I'm not alone. I'm with someone who has the same thing that I drink, that we have and Ja... Ja it helps".

The above extracts illustrated how some of the participants felt lonely at times like they are alone with their worries and struggles, the only ones with HIV, and therefore they felt comforted having others who they feel are like them. They seemed to have a feeling of 'sameness' with other adolescents who are HIV positive and on ARVs. This experience of a shared identity seemed important to maintain as it helps them feel less different and instead makes them feel a sense of belonging and that they are not alone.

5.3.2. Not knowing and needing to know how they got HIV

Knowing their HIV positive status seemed to have motivated the participants to educate themselves around the illness. Their wealth of knowledge of how one is infected with HIV was substantial and seemed to have resulted in them questioning how they were infected and seeking answers. The participants that did not know how they were infected seemed to have a strong preoccupation with finding out how they were infected. Some of the participants seemed really invested in gaining this information, as not knowing appeared to be difficult for them. Along with the need to know how they got HIV, the issue of who is to blame for their being HIV positive was also evident.

Tebogo explained how frustrating it is for him not to get the answers he wants and his investment in knowing how he was infected is evident in his statement below:

> Ah I don't know where, maybe I was born with the HIV disease and stuff, cause I don't quite remember and stuff. Okay, I take it easy cause I been asking, asking, asking, from doctors from everyone who knows about me. And their busy telling me, I don't know, he doesn't know, go ask who, go ask the doctor, go ask someone. They don't know. I just keep it cool okay... Mmm, sometimes I feel okay, if they don't answer me I just feel like okay, why do I have it, Why (whispers). If no one knows why do I have it. How did they know that I have HIV positive, if I'm HIV positive I mean. How did they know. If they don't know how, why did I have this. How did I have this I mean.

While Tebogo's comment reflected a strong wish to know how he was infected, it also suggested scepticism with regards to those who are telling him that they do not know how he was infected. His whispering also suggested a sense that he suspects that something may be being hidden from

him. Tshepo shared how surprising and confusing it is for him and his family that he tested HIV positive as he was born HIV negative:

> And my granny, obviously, they told her, and she was surprised... like she knew that my mother and father didn't have HIV, she was so confused about that...I think from when I was born...Yes they didn't have it, and like my granny was so confused about that, I don't know why, and even I was so confused why. When I ask my dad, he's like we never had HIV, your mother was healthy, even me too I was healthy. Then I say ok, I'll pass through this...

Tshepo seemed to be expressing his need to know how he got HIV and it seemed that not knowing was difficult for him as he was confused about how he can be HIV positive when his parents are not. A part of him might feel that something was being concealed and that he may never know, so he has to find a way of moving on without the truth he wants. Pule also shared what a shock it was to find out that she is HIV positive as she had no idea how she got it and neither does her mother who hurts about this but tries not to show Pule her hurt so as to protect her:

> Cause but me I don't know, I was born healthy, yes just I was sick, sick, sick. It's the only thing that is getting my heart sore because I don't know where this thing comes from... Mmm that was scary... Because I didn't know where this HIV come from. Yes. That's the thing make me scared... And ah, at hospital their asking me. I'm not sleeping with the boys. I don't have boyfriend even now... I'm not feeling well because I don't know who's this thing, where this thing comes from... Because the next thing it makes me shocked. I was born healthy now I was sick, sick for a long time. Yes so now it's this, I'm taking my tablets... Mmm even my mother she wasn't know it. You can see that she's feeling pain but she doesn't want to show me... Um, because... I'm also going to feel the pain.

From the extracts above it could be seen that there is a need to know how they were infected. It was also evident that many of the adolescents had gone about inquiring from their families and health care providers but many of them felt that they had not received satisfactory responses. This seemed to have resulted in feelings of frustration, feelings of shock and confusion and also deep sadness. The participants conveyed a sense that if they knew where the HIV in their bodies

had come from then they would better be able to deal with it. The not knowing seemed to leave them stuck and struggling to fully process their HIV positive status.

Tebogo explained how important it is for him to know as he would know whether it was something he did or that someone did to him and also how to protect himself:

> If I got HIV from sex I'll always tell myself why did I, why did I have to do that and stuff. If I knew why did I have to do that, if I didn't, okay, okay for example if I didn't know that okay there is a disease called HIV positive, I could have made a mistake, okay that was my mistake, oops. It was my mistake, I did a mistake, I know I'm the one and stuff yah, I'll just, I'll just take the blame usually. But if I knew that it was something, needles and stuff, I'll blame other people for not taking care of me, for the needles and stuff. You are not supposed to put needle near me and stuff, like needles and stuff. Yes... Yes. If I knew that I did it, okay, I'll put the blame on me but if it was like needles like I said, yah I'll put the blame on them... I'll be aware, like when I found something, okay this is dangerous, like this is dangerous okay, go put it away, throw it away, do something with it... Yah, I'll be, I'll be prepared for anything. Like when this happens I'll take action, okay this happens I'll take action, when you alone, I'll try stand up for you and stuff. Right now I'm trying to figure out for myself, if I, if I find a solution from where I get, okay, I'll try understand and try to control it a little bit, when I'm okay I'll start doing whatever I do.

Tebogo's statement above reflected a sense of wanting to feel more in control of his life, his status and his body. His comments seemed to be in reaction to a helplessness that he feels with regards to how he became infected. This can be seen through the slight irrationality in his statement, that if it was through his own 'mistake' that would be fine, but that if it was someone not taking care of him 'properly' then he would have someone to blame, and that if it was through 'dangerous needles', he could then know what to do and 'take action', he could 'put them away', however, none of this knowing, blaming or taking action would change his status. Thus, in his case 'knowing how he became infected' seemed to represent having greater control over his illness and his life. Pule expressed how important it is for her to know so she can understand what happened to her:

> I want to know cause I don't know which this thing come from and they saying my sister she was sick they say it's then but I was staying with her. At this time I was not sick, I

> was started sick that time... Yes, so I don't know I didn't find someone who'll explain to me, yes. Also my mother she think that it's my sister but she don't know properly.

There were lots of questions and a strong preoccupation and as illustrated above there seemed to be a sense that the not knowing makes them stuck and due to this they may struggle to fully accept their status, as there is this big piece of the puzzle missing which is "How did I get this". The other thing that emerged strongly in the above extracts was a sense of who is to blame, who did this to me and how did they do it? The wish to externalise the blame suggested a sense that the HIV is linked to a feeling of being persecuted and a struggle to integrate their HIV positive status into their identities.

5.3.3. Secrets and fear of rejection

Fear of what others will think

There seemed to be a strong fear amongst most of the participants that their HIV negative friends and peers would abandon or ridicule them if they knew that they were HIV positive. While some of them seemed to imply that their friends would continue to accept them and be okay with it they still chose not to disclose their status to their friends. Tebogo shared how some people rejected him once they knew he is HIV positive. He also expressed his uncertainty around whether his friends would accept his status, but he tended to lean more towards a feeling that he would be rejected:

> Some other people can say okay, he is HIV positive ah, he is not my child and I don't give anything okay, I'll actually even dealt with it... Um, okay my friends are people that support each other and stuff, I think they are going to be okay, to accept it. Like ah, everyone is normal and stuff. They were going to accept it but things would change a little bit cause they would get familiar and stuff, that guy is so, so, so, and I have to get so so so, not me and him and stuff and stuff. They will think otherwise and stuff, so I would rather keep it to myself.

Sipho described his fear to take his ARVs in front of his HIV negative peers as he fears that they will make fun of him: " I'm scared to take the medication, eh, if my friends that doesn't have HIV, I'm scared. Yes, because I don't trust my friend... I was going to leave them... Because they gonna make me like I am a joke or something else". He also expressed that he is comfortable

with those that do know his status but that they must keep it a secret: “I feel ok because I told them that they must not tell anyone that I have this thing”. Tshepo shared how he prefers that his friends do not know his status as then they cannot use it against him: “Ah for me ah, if they didn’t know it’s ok because, like, when I’m, one day I can fight with one of them, they will say everything, you know then I will feel like I can kill them”. Pule explained how if her friends knew she was taking ARVs they would not want to be her friend anymore so it is best not to tell them:

> Because they’re talking can’t be her friend, what, what, but actually one person knows, my friend is know R, even her brother take ARVs the small one she know it and her mother. Yes I tell her once and she understand but the other friends they don’t know. Yes... They will not play with me or they’ll laugh at me. Yes ...Yes, but only R she know it for my friends, but the other ones don’t know.

Being HIV positive seemed to be something that is difficult for the participants to share with their peers. There seemed to be some ambivalence around whether to share their status with their peers, due to a difficulty trusting them with their status. This also seemed to be a difficult thing for the participants to discuss. This could be seen in Tebogo’s tendency to contradict himself, the vagueness with which he speaks and the more pronounced dysfluency in his speech when discussing what it actually means to disclose his status to his friends. The topic seemed to evoke a lot of anxiety related to their fears around what their peers would do if they knew their status. This lack of trust is what seemed to influence their decisions not to disclose their HIV status. It seemed that they would like to trust their friends with their status but the risk seems too great, so instead they choose not to disclose to their friends. It appeared that living with this secret was felt to be safer for them than trusting and being rejected.

Tebogo shared how difficult it is to trust his teachers with his status as he fears that they may use that information to humiliate him:

> Mmm, No, unlike, okay teachers that’s a big thing, teachers, teachers they might laugh at you make jokes with you okay, tell you you’re my favourite kid in the class and stuff but when it turns to that stuff, he doesn’t even care, he’ll even embarrass you in front of the

> class, don't talk you something, something, something taking medication and stuff, and worsely I can't shut up, I can't ... Yes, I don't trust anyone, especially teachers.

The above extracts indicated how some of the participants worry that if people knew or that those who already know their status may use it against them. This fear of rejection does not only include their peers and friends but there is also a sense that at school they have difficulty even trusting their teachers with their status. Trust seems to be difficult for them and this results in a need to protect themselves, as will be highlighted below.

Secrets

As indicated above most of the participants seemed to fear disclosing their status and being rejected and so secrets and telling lies seemed to be a way of keeping this part of their lives very private as a preventative measure against rejection, particularly from their friends and families. Pule shared how her status is kept from some of her siblings: "My mother yes and my family they don't know that I know it, it's my sister that one that she is staying at Soweto. My mother told her, my brother. The other one my sister and brothers they didn't tell them". This extract captured how even within the nuclear family, her HIV status is kept from other members of the family. Secrets seemed to be an everyday part of their lives, as it is difficult to trust what someone will do with that information. This fear seemed to be linked to an awareness that HIV is associated with a stigma. Tebogo explained how some people have noticed him taking his ARVs but when they ask him he makes up a story to throw them off:

> Mmm, a few people know but some of them are asking why are you taking tablets, I just like ignore them or just tell them lies like I take tablets for mentally something and stuff, so that to keep them away from me... Um, I just feel comfortable cause they the ones who know not other people know like my friends and stuff, but I take it that easy cause they the only people who know and ah, that's what I want, like not many people to know that I am HIV positive.

Tebogo seemed to be highlighting here that he does not want too many people knowing about his status. It seemed that he would rather his friends and people think that there is something mentally wrong with him than for them to know the truth of his HIV status. Tshepo said that he

sometimes feels that he can ask his friends to wake him up, but that he will not reveal why or what he is doing:

> Like my friends would tell me it's 6 o' clock, and I'll ask him in the morning, please wake me up at 6... I just go outside and drink water. When I came back I slept; then he'll ask "what's going on with you?" I'm like no I just wanted to drink water at 6, I'm just lying to them... and I'll like when you ask me, 'no, you are asking the wrong guy, me I don't take that, no ARV', but inside my heart I know I take them... sometimes I feel like to tell them but, I just save it and just keep it in my heart and in my mind.

The above extracts illustrated how some of their HIV negative peers have noticed or are aware of them taking their ARVs and how they have to come up with alternative explanations as to why they are taking medication. The issue of trust seems to be a strong factor and it seemed to create a push-pull internal tension, as to whether they should share their status with their friends. Tebogo shared how he noticed someone at school with the ARV bottle, whereas he prefers using the medication box which conceals the medication he is taking:

> Like this other, like girl when I was still attending at [name of school]... Like she use to take medication like each and every like meal time, 3 times a day. So in the morning at break time and after school, so every time I use to see like every time when he is about to take medication I use to see the paper, the same as mine the paper is the same one that I have. So I'm taking, I'm taking the same, so I'm taking ah the containers for not noticing okay these okay these are medications for ARVs. People are not like charging me and stuff, or I know that thing you took it from where, where, where, I just like know. But when their like, I don't like coming with the paper and stuff, the whole packet, yah. I just like come with the tablets in the container.

Tshepo expressed how he asked his friend who found out his status to keep this a secret from the other children: "Please don't tell anyone, I want to keep this as a secret, and then he said yes, and he never told anyone". He also expressed how his grandmother sometimes reveals in front of his friends that he is on medication, which is humiliating for him and how he makes up an alternative reason for taking medication:

> What I find difficult is that like my granny, what she does it's, like when I go for a visit, she will, like, call me and like "it's time for medication" in front of my friends, and they,

> they will like "why are you taking medication?', and I'll be like "no it's just for TB, it's just TB and fever and they will understand, but I know inside that she did embarrass me.

Being able to trust their family and friends about their status and why they take their medication seemed to also be very important to the participants, particularly as they have a strong fear of rejection. There also seemed to be a sense of shame and embarrassment around being HIV positive and taking ARVs. There were various ways in which the participants go about concealing their reason for taking ARVs: one way is coming up with alternative reasons as to why they take medication and the other way is to not carry their ARV prescriptions in their prescription bottles but rather keep them in a neutral pill container so that they can continue to keep their status private.

5.3.4. Challenges

The participants were also faced with other daily challenges, some of which were developmental and life challenges common to all adolescents, however, these challenges seemed to make it more difficult in relation to being HIV positive and taking ARVs. The challenges that they were experiencing included: negative peer pressure, unstable family backgrounds and for some, mourning the loss of their mothers. Tebogo described his experience with negative peer pressure and his concern that he might give in to the pressure, and he felt that this would be bad:

> When like okay we go party with friends and stuff, party and stuff. I see them drinking and stuff, to make them, okay not, okay, fear okay, they might, they might, overcome you, say okay, drink, drink, everyone's drinking you're the one who's not drinking, okay they tell, they tell you, they tell you. Never listen to that, okay, okay, I do it, I'm gonna drink, I'm gonna drink, I'm gonna drink next minute I'm not there, I'm not okay, okay when I don't know the place, I must stay with them until, if they sleep over then I stay till next morning. When they get up okay we go all of us. If I know the place I hurry up and go cause end up in people like that, ay, it's not a good thing. They might tell you okay drink, drink, sometimes I like, okay, I'll tell myself it's only a taste, it's only a taste. Once you taste one more that's why last time I, last time I didn't want to even know, I didn't want to even go to the party. I just went there and chilled... Yah but I've once tasted it, but ah, I've heard that is nice but yoh, I might end up like ruining my future.

While pressure to drink is a fairly common teenage experience, for adolescents with HIV, who have been counselled as to the health risks of drinking and smoking, this pressure seemed to feel more threatening. Tshepo also shared his experiences of negative peer pressure and what he does to avoid it such as focusing on his school work and sports:

> Like to be a teenager, you see too much pressure from your friends, like smoking, they will be like, "have you smoked before?" And you'll be like "no", then they'll want you to do it. Me, I choose good friends because they used to call them nerds, they will be like quiet in class but talkative in the books... then like ok, let me choose good friends, when they are outside and we are just chilling, they will talk about school work, not girls, not smoking, not gambling, they were just talking about books. Then I started learning from them that gambling, smoking is not good. I never smoked before and I never drinked alcohol before ... even when I'm not playing with the kids, if I just get a soccer ball, I would say 'everything behind me let me focus on this ball', then I play soccer.

These above extracts illustrated the challenges around peer pressure and once again issues around identity and trying to figure out for themselves where they belong and making choices with regard to what is right for them and what is not. There was a sense that to avoid being influenced by negative peer pressure, they have to avoid situations that would result them falling victim to negative peer pressure. Another idea that emerged from the above extract was that one should associate with friends that will not exert negative peer pressure. Focussing on hobbies that keep one out of trouble was also regarded as a way of managing peer pressure. Learning to manage peer pressure seemed important to all the participants, most likely due to their worries around their health.

Even normal teenage things like 'sleeping in' were represented as being dangerous. Tebogo expressed the challenge of missing his medication time in the morning as he sometimes battles to wake up and he over sleeps:

> Mmm, okay, yes, in the morning, cause sometimes my phone don't wake me up, sometimes it's flat, it's off and stuff so I have to figure a way to wake up, I usually wake up early then the time, okay 3am in the morning and stuff but when I am, when I try to get hold of it, stay awake, I just fall asleep and wake up at 8 o'clock and stuff. But the doctor says it's okay waking up late but you have to drink them before 4 hours, okay, so

> I'm telling them ah, you can drink them anytime, but I must, I must get them in time. Not always I must make a mistake and oh, I'm late I must get them in 4 hours and stuff; I just get up at 7 o'clock or something.

Tebogo also explained the stress of going to camp due to the fact that theft occurs there. He worried that his pill box might be stolen, resulting in him defaulting: "Cause some pep, some other boys on camp they turn out crazy and stuff and steal your stuff and end up stealing your medication and stuff, and then you cannot drink and have to wait till you go back home, you'll be defaulting and stuff, yes".

The fear of rejection due to being HIV positive was experienced alongside other fears around competence. Sipho was moved around a lot after the death of his mother at age five and he discussed falling behind academically and how he was made fun of by his peers: "Even now I can't write, I can talk English but I can't write it... Is make me upset because others, my friends at school they laugh me every day if I'm doing the wrong thing".

Pule expressed her constant worry around her health, as before she was prescribed ARVs she was sick a lot, which resulted in her also falling behind at school, something with which she is still currently battling: "It was been hard a little bit, sometimes I getting worried, sometimes I getting well so um, now I have been taking my tablets, yes...Yes, and the school now I'm lating [missing school]. I didn't get school well cause I was sick, sick... It makes me feel painful because I see the other ones getting the high [marks], my friends".

These extracts captured the daily challenges the participants face due to being HIV positive and the processes related to taking ARVs. There were issues around waking up too late to take your medication, as there are set times in which they have to take their medication. There was also the issue of their health fluctuating and also having to go for checkups which results in absenteeism at school and them possibly falling behind. For some this results in a fragile sense of self as they do not feel they fit in amongst their HIV negative peers. There was also the issue of their treatment regimen being changed just as they are getting used to it and this lack of stability seemed to be quite frustrating. While adolescence is normally associated with growing

independence, the need for medication and having to rely on others to make decisions around their medication was also frustrating for the participants. Tshepo described the difficulty of getting used to his medication and then the frustration he feels when it gets changed without any suitable explanation as to why:

> When I'm getting used to it, they change it, then they put another one, and I don't understand what's going on... 3 times....they say, as reason then I was still healthy by that time, even now I'm still healthy, they said they will change them, and I asked my Counsellor, "Why are you changing them, the tablets?" and they say these tablets are for kids. They said it last year when I was 14... then they changed them this year January and again at July...

Sipho talked about losing his mother at the age of 5 and how even today he still wonders about her and still experiences a deep pain from her loss and around the effect that this has had on his siblings and on him:

> Eh... about 5 years, I was busy upset and thinking about my mother, I was don't know my mother, I ask my sister: "my sister, where is my mother?" she take me, he go with me to the room, he explained to me that our mother, she passed away the time I was 5 years old... I cried, cried. My brother comes, my brother comes, and he asks me 'what are you crying for?' I'm crying, my sister told her...him: he's cry crying for mother, he want he's mother back... so if I tell them that my brother, get so... so destructed about that I want my mother, and he start, he started to steal, to go to the jails and come back, go to jails and come back. Now, just now he's in jail for nothing... I was 15, I cried until I bleed.

Masego also shared her feelings of shock and anger after losing her mother:

> Like um, my mother was sick and she was having TB and the she went to hospital to see them um and after that, I went to go visit her and they told me that not for longer then I just stayed there then when I came back um, when I came here, when I came here then my other doctor then she showed me the video of my mother then she told me that it's too late now my mother, my mother died. Then I was like how come it happened then she like I don't know, I'm not always there she's working in the other hospital... It was um sad but I was not controlling my temper, cause I usually have a short temper even when I am angry I do.

The issue of mourning and loss was illustrated above and it seemed that in addition to their worries around their health and their ARVs, many of the participants had also experienced loss of a parent due to HIV. They appeared to be struggling with the bereavement process and for Sipho; the loss of his mother seemed to be so painful that it resulted in him sometimes defaulting with his medication. There also seemed to be a lot of anger around losing their mothers and struggling to manage this. These participants were living in a home and this suggested that most of them have had really difficult childhoods resulting in them staying at the home and therefore, there seemed to be a lot of emotional turmoil that they were trying to deal with in their lives. This turmoil seemed to be linked to their moods and as mentioned previously, their moods seemed to influence their levels of adherence.

5.3.5. Life and death

Living with HIV and understanding why they are taking ARVs and the importance of ARVs seemed also to be strongly linked to the sub-theme of life and death. It seemed that they are confronted with this issue of life and death every day of their lives as they take their medication. They seemed to have to ask themselves everyday to choose to live or to choose death, because that is what the choice of taking their ARVs means to them. Tebogo expressed his sadness related to his internal debate of choosing to take his medication and to live or not to: "I always feel, okay sometimes I feel sad, I ask myself should I live, should I don't, should I, should I, okay I just come to a point where I stop. I drink my tablets in order to live, that's it". Sipho described his understanding that if he does not take his ARVs it means death: "They say, this thing, this medications, I have to drink them until I die. If I leave them, I am going to die... Eh, ARVs they said, if I leave them I'm going to die or I'm going to be thin. I say ok, they teach me about ARVs". Pule shared how life was easier before she found out she was HIV positive as she did not have to constantly worry about death, as this is very scary for her: "Because when you take your tablets like that time you didn't take it, it was better because you don't think I'm going to die or something, yes... It feels scary too much scary. I'm asking myself... Why this thing about that, but my doctor did tell me I have to take my tablets all the time". Death seems to be something with which they are preoccupied, as it has been linked to their meaning of ARVs. Taking their ARVs means life and not taking them means death. Even when they contemplate

not taking their medication, the thought of life or death seemed to influence their decision to take their ARVs.

Tebogo expressed that some of his peers want to or have given into death and have lost hope:

> Most of the teenagers could tell themselves ah, I'm done with life why should I drink medication, I won't reach 20 years, I won't see 20 years in the future, I won't see this HIV in the future. If they hope in their selves, and believe in their selves they might reach there... Some teens they don't tell themselves, okay I can make it. They always tell themselves negatively, no I won't, I won't reach there, that's why many teenagers who are HIV positive kill themselves or do something, or smoke or do drugs, or drink, cause yah, cause they tell themselves I ain't gonna reach there and if I don't and nothing will stop me and stuff, ah, I will rather do this and that in order to not reach there.

This theme of death was also linked to a sense of hopelessness and as the above extract illustrated, being HIV positive has led to some adolescents losing hope and giving up on their lives as they do not feel that they will live long. Therefore some give up but it seems that some choose life and for them that means taking their ARVs.

5.3.6. Defences

The defence mechanisms that help the participants to manage living with HIV and taking medication every day of their lives were quite clear during the interview. When asked certain questions, they were either quite vague or sometimes were inconsistent about their experiences particularly with how they feel about their status, having to take ARVs and around the issue of defaulting. Tebogo described his coping mechanism when dealing with the horrible taste of his ARVs. He does this by telling himself his ARVs are sweets:

> No, I was a little bit surprised at first but as I carried on with the medication cause it was a little bit sweet and stuff I took it just like sugar, sweet and candy and stuff cause it had, it had that, that, sweetness inside it so I just every, every morning and night when they say medication I just remember sweets...

This seems to help him to take his medication even though he finds the taste and the idea of his ARVs almost intolerable. Tebogo also shared a particular interaction pattern that he has with his

guardian where there is an avoidance of dealing with the seriousness of taking his ARVs: “Yah I feel safe because he is the only one who knows and stuff, he not gonna do like, okay, you gonna die by HIV and stuff. Okay we all make jokes, yah we all make jokes but you must drink your medication. I tell him why? It’s obvious you already know why you asking and we laugh and laugh and you drink”. This extract seemed to suggest some avoidance of talking about the more serious implications of not taking ARVs, but rather an engaging with the frustrations and worry in a more playful way, perhaps indicative of a degree of manic defence.

In the following extract some splitting was highlighted, as minutes before Sipho expressed that sometimes he does not adhere to his medication, however, when I asked again, he contradicted himself and said he does not default. He said: “Eh I take it eh, everyday... everyday”. When asked how often he is found to be defaulting by his doctor he responded: “Aah, I don’t know”. This suggested some defensiveness around acknowledging his defaulting. These responses illustrated a splitting between the times when he is taking his medication as he should be and the times when he is not taking his medication as he should. He was aware that he should not be defaulting, and this knowledge appeared to make it difficult for him to engage with the topic of defaulting for too long. This ‘not knowing’ seemed to help him manage. Thus he separates in his mind the good him who takes his medication and the bad him that does not adhere.

Tshepo shared his denial when he was first told about his status: “I didn’t believe it”. This shows how finding out that he was HIV positive was such a shock that he initially went into a state of denial as a way of managing the difficulty of finding out his status. Masego illustrated her confusion in how she felt about taking ARVs: “They told me that the medicine was for HIV, I don’t know. I was HIV and then my mother was having TB, I don’t know. Okay fine I am proud of it cause I feel like I am going to be alive. I am proud of it”. This also seemed to indicate some denial of hers and her mother’s status when her status was first disclosed to her and a difficulty with it and how she even takes a more positive view of her status as a way of deflecting from the difficult feelings of what it really means for her to be HIV positive and take ARVs every day. Denial seems to a defence that was and is strongly adopted as a way of dealing with the difficulty of being HIV positive.

Sipho's extracts are indicative of how when it came to talking about him not adhering it was difficult for him to engage with it for long therefore he splits off or avoids it and this was indicated by some inconsistencies with his responses to the questions. Tshepo's extracts show how difficult it was for him to find out about his status and when he was asked how he felt he describes being in disbelief and possibly indicating an initial process of denial which allowed him to manage how difficult it was to accept his status. There was also a process of denial with Masego as she seemed to be very vague, unsure and inconsistent about how she felt about finding out her status and why she was taking ARVs. Being HIV positive and taking ARVs brings a lot of challenges and difficulties and as a way to cope or manage the participants seem to be spitting at times, avoidant, vague, inconsistent or denying their thoughts and feelings about their status.

5.4. Process of acceptance:

This sub-theme examined how the participants go about trying to make sense of being HIV positive and having to take ARVs every day for the rest of their lives. It particularly captured their process of accepting their HIV status and having to take ARVs. Tebogo described his experience of not knowing how he got HIV and how he goes about trying to find a way to move on without knowing:

> I get angry but not that angry, I'll just say okay it's my fault, I'll tell that I'll deal with it, cause it's me no need, okay, when okay, who's HIV positive, me not them, so whether I beat them or hurt them, what try to kill them or when I'm angry it won't help nothing, I won't gain anything it will just put the blame on me and that's it... I usually like, yes, I usually like write down like how can you get HIV po...HIV disease. Like I count them then I like, I then I memorise what I can remember when I was a little kid. I memorise everything what I can remember... Mmm, right now I haven't come up with anything cause I've been telling myself, okay, I HIV, okay I was born with it, that's it cause I can't find any solution so just say okay I was born with it now I will live the rest of my life with it.

There are powerful emotions being illustrated in Tebogo's quote around his struggle with processing and coming to terms with his status. While he was expressing his anger about not getting full disclosure from people around him, underlying that there was also a sense that he is

feeling deep sadness, helplessness and desperation, all of which are involved in him coming to terms with his HIV positive status.

Tshepo expressed his feeling of anger and confusion about his status and how watching the local series for children helped him to think about and begin to work on accepting his status: "Confused, angry, then shout, I wanted to say, say "stuff HIV!" ...and like I used to watch too much TV, then I will watch Soul Buddyz, then they'll be talking about HIV, then I think about me, they say 'you can live with it but don't tell anyone'...that's what I got from there, and then I just put it here in my heart, then I just say Ok, let me just accept it. Then I just go, pass through it, then I got used to ARVs".

The above extracts illustrated the process of accepting their HIV status and how initially there was anger and blame and a need to know how they got it. The issue of 'how did I get HIV?' was mentioned earlier and in this section the process that the adolescents move through is evident. Not knowing and trying to move forward without the answers seems very difficult. There is a process of reasoning and a need to let go of the focus on the how, and rather focus more on the present, which is that they will have to live with it for the rest of their lives. There also appeared to be a process of accepting that it is not a death sentence and that they can live with HIV, particularly through taking their ARVs.

Tebogo shared how he was able to accept taking ARVs by equating them to medication he had been taking before the ARVs. Through thinking of the ARVs as he thought about the other tablets, he seemed better able to make the transition to ARVs:

> Ah, I was, I was, I wasn't that surprised cause I was use to taking meds, I wasn't that surprised I was like okay, I will carry on like each and every day ... So I just prepare myself I say, okay If I want to live I should just drink them... So like I'm trying to go to school, I know I have a talent in this and that but I'm not quite sure if it might help me in the future. I want to be a scientist, that's what I want to be, nothing will stop me being a scientist.

Tebogo's quote above illustrates the importance of hope in the process of acceptance. Sipho described his process as taking time to accept his status and make a choice to start taking ARVs. He felt that one of the reasons that he was motivated to take his medication is so that he can take care of his sister. This role and responsibility appeared to be important to him:

> Oh the time I was starting taking ARVs, eh, they test me and they ask me if I'm ready I must come to the hospital and tell them that I'm ready. I sit, eh, maybe 3 weeks; next, after 4 weeks I go to tell them that I'm ready now to take my ARVs. They give, they started me, they give a card and some medication, and I bring them in N.H... Ah like, if I'm take those pills, I'm taking not for me alone, for me and my sister to support my sister... Eh, because my sister loves me very much, to me, to me, he like, she's like my mother or father.

Tshepo described how sometimes he gets angry and does not want to take his medication but how at these times he is able to focus on the benefits, which motivates him to accept that he needs the medication and adhere to his treatment regime: "Nna, I'm used to it. I would say is very true to keep healthy, like uhm, to be active... Sometimes I feel angry, like I don't wanna take it, I just wanna go away, but I think twice. If I run away... my medication, who's going to help me, and who's going to make sure that I stay healthy". This statement also highlighted the role of supportive others in managing being HIV positive and adhering to treatment. Tshepo suggested that he chooses to stay so that he has people around to help and support him.

Tshepo also described that with time he has been able to get used to and accept taking ARVs and that through this process he has managed to feel that he is no different to the children that do not take ARVs: "Ah for me, it perfect because I used to take them when I was 12, 13, 14; now I'm getting used to them, and like, ah let me see, I'm the same like the other teenager who doesn't have HIV, who doesn't take medication... I'm used to it now, I know this time it's medication time, then I have to go and take medication". Masego expressed the importance of not being ashamed as this is her reality which allows her to accept her status: "Some of my friends they do know, those that stay here they ask me yah, they ask me 'are you proud of that?' then I'm like 'yah I'm proud of it, there's nothing I can do'". Tebogo described the importance of being hopeful that there will be a cure and this helps him to accept the reality of having to take his ARVs until there is a cure:

> I always, I always think okay, things will work out. I always think positively that things will work out, there will be one day okay a cure for AIDS, there'll be one day, as long as I'm taking, but when I give up my hope is gone as well, like when people hope okay, like okay, let me do like this, okay, out of 100%, 75 % people hope that okay there is gonna be a cure for AIDS and others are making, like they trying to figure out that, um, 15% or 25% is busy like figuring, like, okay, I don't know how we gonna do the cure for AIDS and stuff... if we believe it might be there but if we don't believe if might kill, might kill other people. So I just put my belief in that, that there is gonna be a cure and I must keep on pushing.

These extracts illustrated a process of meaning making. It appeared to be a highly personal process, in which each participant had to make peace with their status and figure out on their own ways to manage the difficulties and challenges associated with being HIV positive and taking treatment. The process seemed to involve taking into consideration all they have been told and their understandings of the purpose of them taking their ARVs. It seemed from the above extracts that this process involves constantly making a choice to take the ARVs. Hope for the future, a feeling of belonging and purpose and a certain drive to reach certain goals seemed to motivate them to accept the importance of taking ARVs. Struggling through the anger and helplessness also seemed to be important as it allowed for an acceptance that they cannot change how things are and that it seemed better to accept their reality. It also seemed that with time the participants have been able to work through the more difficult feelings and have developed coping mechanisms. Some of these included occasional avoidance and humour. Another important aspect of accepting the current situation was having hope and holding onto it. Holding onto hope that there will be a cure seemed to help the participants to accept, to some degree, their current reality of having to take ARVs every day. It also seemed that with time they are able to get used to the lifestyle of taking ARVs and some were even able to shift from a space of feeling alone and at risk of rejection, to being able to identify with their HIV negative counterparts.

5.5. Self-Reflexive clinical impressions

The following section is a first-person written account of the researcher's experiences conducting the study in order to explore her own assumptions and influences on the study. Reflexivity is an accepted tool that is used in qualitative research process (See end of Ortlipp, 2008); in which

researchers are encouraged to reflect on their presumptions, choices experiences and actions during the research process (Mruck &Breuer as cited in Ortlipp, 2008) . It is thus for researchers to be cognisant of their emotions, assumptions, values and also how the participants may view him or her during the research process and this shall be reflected upon. The researcher was inspired to do this research study due to the work she used to do with HIV positive adolescents in Botswana. The experience gave her some insight into some of the challenges that adolescents experience and in particular to the challenges in ART adherence. This motivated her to do this research in order to really understand the adolescents' experiences. The researcher's experiences in conducting this research was both emotionally challenging yet enriching in understanding the adolescents' experience of ARV adherence. The research met her assumptions that adherence to ART is quite a challenge to a point that non-adherence is common for both the participants in this study and some of their peers.

Upon the first visit to the shelter to meet the adolescents, most of them were still on their way back to the shelter from school so the researcher had to wait. The adolescents came in one by one and the researcher had to start and stop introducing herself and the research study. The researcher was able to do an introduction and after that only Sipho came up to her to say he wanted to do the study. The researcher felt quite discouraged as she was unable to reach more of the adolescents. Upon coming back to the home the researcher found out that none of the females at the one shelter wanted to be part of the study and with further inquiry from the guardians at the home, the researcher was informed that they possibly did not want to be part of the study as they tend to default (not adhering) and possibly did not want to be open about this. I felt such disappointment as I felt that they were the right people to talk to, as one of the main aims was to understand why the adolescents are defaulting. However, it appeared that acknowledging the defaulting is difficult in this particular population.

The researcher started the first interview with Tebogo who was quite open which allowed the interview to flow. However the researcher felt that at times Tebogo was not being authentic as though he was trying to present a positive picture and avoid his difficult emotions. He was guarded regarding talking about the more difficult feelings which were characterised by

avoidance of answering certain questions as he was vague and dysfluent in his responses. The second participant was Sipho, who had approached the researcher on her first visit to the shelter and informed her he was very interested in taking part in the research study and sharing his story. As much as Sipho was very interested in taking part in the study it was very clear during the interview that remembering and talking about his past and his experience of living with HIV was quite difficult for him. Sipho was very emotional during and after the interview. It was quite a difficult interview, as the researcher felt guilty about unearthing these difficult emotions; however, it seemed that he experiences these emotions regularly and that he needed that space to share his story instead of being quiet about it. The researcher also found that during certain points in the interview Sipho was open about not adhering while at times he would say the opposite to that effect. This indicated some push pull relationship with adhering and not adhering and how at times it seemed difficult to acknowledge non-adherence as he is aware that it is not good to default. Pula also had quite a difficult time talking about her experiences, particularly as she recently found out that she has HIV, unlike the other participants who have known their status for some years now. She worries about being rejected by her peers who are HIV negative and also because she does not know how she was infected. Pule was quite open during the interview but it was clear that out of all the participants in the study, her pain was still raw and she had not started her process of acceptance. The researcher felt a strong sense of wanting to be able to give Pule the answers as to how she got infected. It was clear that she was really struggling with the not knowing and it made me feel helpless. Tshepo seemed quite indifferent during the interview; he was very direct and tended to give short answers. The interview felt quite short and it seemed like Tshepo did not really want to take part or talk to the researcher about his experiences. This made the researcher feel anxious. However when the researcher went through the transcript she realised that the interview was rich with information and that Tshepo had in fact been able to tell his story. Masego was quite avoidant of her emotions as she struggled to express her affect and would say that everything is fine, but struggled to express what “fine” was to her. She, however, was quite open in talking about her experiences.

Hearing the participants’ life experiences of living with HIV and having to take ARVs was emotionally difficult for the researcher, particularly when the participants themselves were

emotional. Hearing their stories brought feelings of sadness that these adolescents have to deal with all the difficult life challenges that they face. The thought that their childhood is not as free or carefree as their HIV negative peers was particularly sad. It seemed a heavy responsibility for these teenagers to have to make "life-death" decisions every day, which seem to be such a burden physically, emotionally and socially.

5.6. Conclusion

In this chapter the results of the study were presented. The predominant themes were: the adolescents' relationship to the ARVs; the integration of ARVs into identity; and the process of acceptance. The participants' quotes were used in the explanation of the themes in order to provide insight into the adolescents' experiences of living with HIV and having to take ARVs everyday of their lives. This chapter also included an understanding of the challenges that the adolescents grapple with in their lives, and how they try to cope, manage and overcome these challenges. It also illustrated the different factors that help them to manage living with HIV and adhering to their medication. Within this chapter the researcher also provided a self reflexive review which provided an authentic observation of the adolescents experiences and how the researcher experienced the interview, also her understanding and insight on a bigger scale of how the adolescents experience living with HIV and adhering to ARVs.

Chapter 6: Discussion

6.1. Introduction

The aim of this study was to examine and gain an in-depth and unique understanding of these South African adolescents' experiences of living with HIV and having to adhere to ARVs. This chapter focuses on discussing the results of this study in relation to other research studies on this topic and those related to this topic; along with the theoretical implications of these results. The discussion consists of three sections, which are as follows: HIV positive adolescents' experiences with ART adherence, the factors that help adolescents adhere to their antiretroviral (ARV) medication and the challenges that they experience in adhering to their ARV medication.

6.2. HIV positive adolescents' experiences with ART adherence

The adolescents' experiences with ART adherence is captured by the sub-themes: the importance of disclosure; the struggle to develop an identity; and choosing to live. This section highlights, from the perspective of the adolescents themselves, the importance of disclosing to a child or adolescent their status, especially with regard to helping them to renegotiate their identity. Adherence to ARVs as being an aspect of their identities that needed to be managed emerged as a predominant theme and included the negotiation of peer relationships. A link between taking ARVs and being alive that was found in the interviews is also explored.

6.2.1. The importance of disclosure

This study found that the adolescents' understanding of their medication included their processes of becoming aware of their HIV status. A strong link emerged between their understandings of their medications and how they were told about their status and the reasons and importance of their ARVs. Several studies have found that disclosure to a child or adolescent with a chronic illness, such as HIV, is important in improving their lives (American Academy of Paediatrics, 1999; Kubler-Ross, 1970 & Vaz et al., 2010). This study supported these findings as disclosure seemed to be a turning point for the participants. Disclosure appeared to create an expansion of awareness, the beginning of them acknowledging their HIV status and also an awareness of why they need to take their ARVs. Disclosure began a process for the participants of trying to make

sense of what this meant to them. This meaning making then seemed to allow for a new awareness and understanding, which they applied to their lives.

The initial experience of disclosure brought about an array of negative emotions for the adolescents in this study, such as disbelief, shock and sadness. This supported the findings of a study undertaken by Vaz et al. (2010) which indicated that the disclosure of an HIV positive status to a child initially evoked feelings of sadness, relief, worry and being heartbroken. Some of the reasons for these emotions were specifically due to the stigmatising nature of HIV (Vas et al., 2010). For the participants in this study, the initial experience of finding out about their status, the need for taking ARVs and the importance of adhering to their ARVs also initially seemed to be quite overwhelming and emotionally difficult.

Some of the participants described difficult experiences with their ARVs prior to disclosure. One of the participants described not knowing why she was continuously taking medication without stopping, and only through her HIV positive status being explained to her did she gain an understanding of the need for her to take medication continuously. Another participant also expressed not knowing why she was taking the medication, but instead only knowing if she did not, she was going to die. Thus, it appeared that not knowing was frustrating and possibly riddled with a fear of death for these adolescents. This highlighted the importance of disclosure, as not disclosing to the child or adolescent can have negative consequences. This finding supported the findings of the American Academy of Paediatrics (1999), who also found that a child can develop inappropriate negative fantasies about their illness. The adolescents expressed how being disclosed to and also gaining knowledge helped them to acknowledge the importance of taking their ARVs correctly. This has allowed them to begin processing what it means for their lives to be HIV positive, what it means to be on ARVs and the importance of adherence. Given time to process the implications of their status seemed to be more beneficial to the adolescents' understandings and overall awareness, which is what Vaz et al. (2010) also found in their study. However, it is interesting to note that in this study none of the participants knew the term 'adherence' but rather referred to 'defaulting', referring to skipping medication or not taking the medication as instructed by their health care provider.

Disclosure seemed to be a significant issue amongst the participants and represented in their minds knowing their status, knowing why they were taking ARVs and also understanding the importance of this. This was most clearly evident in the sub-theme 'not knowing and needing to know how they got HIV'. This theme really highlighted the importance of full disclosure and allowing the adolescent space to ask their questions about their status, as this seemed to be an essential part of their process of understanding and trying to come to terms with their HIV positive status. Other studies conducted with HIV positive adolescents have shown that delayed disclosure is a psychosocial problem experienced by these adolescents (Amberbir et al., 2008; Ferrand et al., 2009; Farley et al., 2006). An issue that appeared with these participants was that of knowing how they got infected, as those who were not told how they had contracted HIV seemed quite preoccupied and invested with finding out this information. This was evidenced in how motivated the participants appeared to be with regards to seeking out information to educate themselves about the illness and how one can be infected. Their enquiries of how they were infected, however, appeared to be met with evasiveness from their parents or caregivers, which appeared to trouble certain of the participants. Some of the feelings that were evoked were anger, frustration, confusion, sadness, helplessness and possibly mistrust from the non-disclosure of how they were infected. Vaz et al. (2010) found a similar process occurring in their study where non-direct responses from parents about the child's status had an emotional effect on children, such as sadness and worry. The current study also found that the issue around how they were infected appeared to be an attempt to find who is to blame for him or her being infected. There seemed to be a sense of guilt for being HIV positive and the adolescents seemed to be trying to figure out if the guilt is theirs to keep. The participants conveyed a sense that if they knew where the HIV in their bodies had come from, that they would better be able to deal with it. For one of the participants, knowing how he became infected seemed to represent having greater control over his illness and his life. Vaz et al. (2010) also found that most children and adolescents wanted to know the source of their infection, confirmation of the diagnosis, about getting better or cured, and about AIDS being fatal. However, despite this wish to know, their study found that most of the participants did not ask their parents or caregivers for this information (Vaz et al., 2010). The not knowing seemed to leave many adolescents stuck and struggling to fully process their HIV positive status. Knowing more about the illness seemed to bring positive effects to

living with the HIV. The more they know about their status and the purpose of treatment then the better adherence, self-management behaviours and adjustment. Vaz et al. (2010) study also showed that disclosure helps with improved adherence and can give a sense of peace and relief from finally learning what was causing their illness and their suffering so that they could now take care of themselves. Adolescents who knew their status tended to have a higher self esteem and better coping skills as compared to those who are unaware of their status (American Academy of Paediatrics, 1999). This was confirmed in this study, which found that disclosure appeared to be important with regards to providing adolescents with a space where they can really open up, ask the questions they need to be ask and for these to be appropriately answered, so that they can continue their journey of making sense of this for themselves.

6.2.2. The struggle to develop an identity

Knowing their status and understanding why they were taking their medication also influenced the identities of the adolescents in this study, as was found in the sub-theme of 'experienced identity'. Blos and Erikson (as cited in Balk, 1995) believe that adolescence is a time for self discovery and finding a purpose and interest in life which is a natural process. This sub-theme captured these adolescents' processes of self discovery, and in particular, how they perceived themselves as HIV positive adolescents, particularly in relation to their peers, both those who are HIV positive and those who are HIV negative. Some of the participants expressed their concern and anxieties around being the only ones with HIV and having to worry about taking ARVs when their peers do not. There was a sense that they feel lonely, as though they are the only ones with HIV and taking ARVs. Being with their peers who also are HIV positive and taking ARVs seemed to alleviate this sense of loneliness and helped them to find a place of belonging. One of the participants expressed this in the following statement: "Ah I feel like, ok, it's not, uhm I'm not alone. I'm with someone who has the same thing that I drink, that we have and Ja... Ja it helps" (Tshepo). This shared experience seemed to ease the burden and pain of loneliness as they felt comforted by having access to someone else who could understand their challenges and pain. This sense of a shared identity seemed important to maintain as it helped them feel less different, that they belong somewhere and that they are not completely alone. The adolescents in this study may have been able to have this more readily as they lived in a shelter with other HIV positive

adolescents, however, it seemed that it was harder for them when they were away from the shelter, such as at camps, at school or at their homes as they were then faced with feelings of loneliness and the pain of having to worry about what to do with their medication and even wondering if there were other adolescents like them who are on medication. Blos (as cited in Balk, 1995) also described adolescence as a time of vulnerability, ambivalence and conflict. He wrote that early adolescence is marked with a lessened identification with parents, increased identification with peers, intense involvement with causes, and infatuations with an opposite-sex peer. It seemed that this was what these participants were experiencing. However, in their struggles to figure out their own identities, being HIV positive seemed to complicate this for them. Having HIV and having to take ARVs seemed to make it more difficult for them to identify with their peers, leaving them feeling lonely, vulnerable and possibly ashamed, which appeared to make it more challenging for them to feel like they fit in.

Most of the participants in the current study really felt like they were different from their HIV negative counterparts which seemed to disrupt this developmental stage of an increased identification with their peers. They expressed feeling different from their HIV negative counterparts as they are not as fit and healthy and sometimes it was difficult for them to be the only ones having to take medication, while their friends do not have to worry about this. Taking the medication seemed to remind them of their difference. It is possible that much of this experienced difference could be related to the stigma around HIV. While one of the participants was able to identify more with his HIV negative peers, as he felt that there were more similarities than differences; the other participants were, however, more ambivalent. There were strong issues around identity evident in the participants grappling with whether they belong or not and where they belong. Adolescents between the ages of 13-24 years of age who test positive for HIV are often confronted with a wide range of difficulties as they struggle with ‘‘normal’’ adolescent developmental issues while carrying the burden of living with a highly stigmatized and life-threatening illness (Hosek, Harper & Robinson, 2002). Being HIV positive and taking ARVs appeared to be something integrally involved in their process of identity formation. The WHO (2009) reported that all adolescents, including those who are living with HIV, face difficulties of a personal nature such as self-awareness, defining their identity, building their peer

group, making plans for the future, and dealing with their sexuality. During this developmental stage adolescents are taking the step from childhood into adulthood and this is hard in a variety of ways and causes inner conflicts such as stress, confusion, and an identity crisis. HIV appeared to add to this developmental crisis, as they appeared to have to find a place to fit their HIV positive status into their identity.

Erickson (1968) viewed identity formation as the critical developmental task of adolescence; and this was quite evident in this study. Chigier (1992, as cited in Hosek et al., 2002) found that identity and chronic illness may often cause a feeling of flawed identity in an adolescent. Marcia (1968) also spoke of different identity statuses which capture the presence of various identity crises and how committed the individuals are in the process of consolidating an identity. However, they seemed to fit into the Identity achievement status (Marcia, 1980) as they seem to be committed to exploring their identities. This was characterised by the presence of hope in the future as most of the adolescents wanted to live and have set goals for themselves instead of giving up on life. However, they also spoke about some of their peers who do not adhere to their medication, as they seem to have given up on life and see no point in committing to their ART as they see no hope for a future. A similar study to the current research found that HIV positive adolescents either fell within identity achievement or identity diffusion (Marcia, 1968), which appeared to influence their responses to living with HIV (Hosek et al., 2002). For some, an HIV diagnosis helped to facilitate and further the identity development process, while for others the opposite occurred, where the possibility that their life is limited and fear of setting goals that might not be achieved, inhibited exploration of identity issues and promoted the avoidance of commitment (Hosek et al., 2002). The following quote from an adolescent in this study really captured and supported what Hosek et al. (2002) found in their study. Tebogo one of the participants said:

> Most of the teenagers could tell themselves ah, I'm done with life, why should I drink medication, I won't reach 20 years, I won't see 20 years in the future, I won't see this HIV in the future. If they hope in their selves, and believe in their selves they might reach there... Some teens they don't tell themselves, okay I can make it. They always tell themselves negatively, no I won't, I won't reach there, that's why many teenagers who are HIV positive kill themselves or do something, or smoke or do drugs, or drink, cause

> yah, cause they tell themselves I ain't gonna reach there and if I don't and nothing will stop me and stuff, ah, I will rather do this and that in order to not reach there.

It seems that the adolescents' attitudes towards what it means to be HIV positive may influence and be influenced by the process of identity formation. When HIV is viewed as a death sentence having hope for a future or setting goals may feel pointless. It seemed that for some adolescents being HIV positive can lead to a loss of hope in a future, which can result in them giving up on their lives as they do not feel that they will live long enough to meet these goals. The participants in this study, however, seemed to view things more positively, particularly as they trust the ART and have hope for a long life in which they can meet their goals in the future.

6.2.3. Choosing to live

Despite hope for the future, the participants in this study seemed to be grappling with the possibility of death. The sub-theme of 'life and death' was evident throughout the research interviews. The participants seemed to be faced with the issue of life and death every single day as they take their medication, as for them that is the choice they have to make when it comes to adhering to their medication or not adhering to their medication. The following quote really captured the internal debate that these adolescents have when it is time to take their ARVs: "I always feel, okay sometimes I feel sad, I ask myself should I live, should I, don't, should I, should I, okay I just come to a point where I stop. I drink my tablets in order to live, that's it" (Tebogo). Kubler-Ross (1970) wrote that to the unconscious mind, death is not possible in regard to the self. However, when one has a chronic and terminal illness this dynamic changes, as one has to directly face the possibility of their death. This seemed to be what was found in this study as the adolescents spoke a lot about death both directly and indirectly. An example of how intrinsic the idea of death was with the participants was captured in the following quote: "They say, this thing, this medications, I have to drink them until I die. If I leave them, I am going to die... Eh, ARVs they said, if I leave them I'm going to die or I'm going to be thin. I say ok, they teach me about ARVs" (Sipho). This illustrated how strong life and death appeared to be engraved in their understanding of their ARVs. It also seemed that their caregivers and heath care providers used the terms 'life' and 'death' when they explained the purpose and importance of adhering to their medication, which may also have contributed to keeping the idea that they

may die prominent in their minds. Having to face and accept possible death can be challenging. One of the participants expressed how life was better before she found out about her status and the purpose of her ARVs, as having to worry about death was very frightening for her. Ridder, Geenen, Kuijer and Van Middendorp (2008) highlighted how one of the key factors that impacts one's ability for psychological adjustment to living with a chronic illness is a negative or positive affect. Good psychological adjustment predicts increased participation in self-management and vice versa (Ridder, Geenen, Kuijer & Van Middendorp, 2008). This indicates that if patients stay in the doom of death this can hinder their ability to come to terms with their illness and adhere to their ARVs. However a positive affect and attitude to life and living makes it easier for psychological adjustment to living with HIV. With regards to the five stages of bereavement that Kubler-Ross (1970) referred to, the participants seemed to have passed through the stage of denial, as they all appeared to have an awareness of what it means to be HIV positive and to have to adhere to their ARVs. Kubler-Ross (1970) wrote that in all five stages of bereavement a hope always exists throughout as all that is being experienced has meaning. In this study, the participants' trust in the ART and their hope that they are going to live long lives seemed to be an important motivator and appeared to help them get through the difficult moments. Positive cognitive processes, emotional regulation and engaging in self-management and self-care behaviour are vital to the process of psychological adjustment to living with a chronic illness (Ridder, Geenen, Kuijer & Van Middendorp, 2008). The participants in the current study did have some moments of a negative attitude and affect but the more positive attitudes and appreciation of life and what the ARVs were doing for their lives allowed them to engage in the more positive self management behaviour of adherence and helped them to come to terms with their status. As there are different aspects to being able to accept and live with HIV practitioners must encourage people to engage in pleasant activities, acknowledge the emotions they have about the disease, challenge the barriers for engaging in self-management, and find meaning in small things (Ridder, Geenen, Kuijer & Van Middendorp, 2008). Meaning making is important as it helps with acceptance and coming to terms with living with the illness. This may take time but it is possible as has been identified with the participants that took part in this study. The ARVs mean life for them and this has brought hope and life rather than death.

6.3. The challenges adolescents experience in adhering to their ARV medication

The participants in this study indicated a number of factors that contributed to their negative experiences of taking and adhering to their ARVs. This was captured by the sub-themes; 'the inconvenience of ARVs, the stigma and fear of ARVs, depression and loss and ARVs, ARVs complicating normal adolescent developmental challenges'.

6.3.1. The inconvenience of ARVs

One participant described his frustration and hate of having to wake up early every morning to take his ARVs. He also expressed his hate for the taste of his medication. The taste sometimes was so bad for him that he wished to 'vomit' out the medication. This seemed also to be linked to a wish to not have to take his ARVs or perhaps a wish in fantasy to 'vomit' out his HIV. Some of the participants complained of the side effects of the ARVs making them sick to a point where their ARV regime was changed. Another study identified that along with bad side effects from the medication, among adolescents there were other factors related to medication that influenced poor adherence, such as pill burden and complications of day-to-day routine (Belzer et.al, 2005). This was not unlike that which the current study found in that these adolescents also got frustrated with the taste, side effects and the fixed routine, such as having to wake up early every day to take their medication. Due to having to take medication at a specific time, it sometimes interfered with their plans, which seemed to annoy them and perhaps felt unfair, as they mentioned that their peers, who are not taking ARVs, do not have to worry about any of these things. The following quote illustrated the inconvenience of taking ARVs: "It's like when I get angry, when they say 'medication time', maybe I'm watching something interesting, then I got their attention, when they say medication, I just stop, my mind can go backwards, feel like I can take the time back, then I get angry, pissed- off, I feel like I can say 'stuff medication'" (Tshepo). There also seemed to be a lot of anger which sometimes led to the contemplation of defaulting. Another participant expressed how frustrating it is to take ARVs as it never stops. They have to take their medication everyday continuously whether they are sick or whether they are well, which felt like such a burden to them. Other studies found that some patients reported skipping doses because of simply forgetting, feeling sick or ill (sometimes due to side effects of medication, being busy and running out of medication) and also lack of social support (Amberbir

et Al., 2008; Abreu, et al., 2008). One participant shared that once his medication had expired but that he had kept taking it as he was meant to, unaware that it had expired, and that when he went to hospital for a check up, they told him he was not adhering which was upsetting for him as he knew he had been. It seemed difficult for these adolescents to bear the heavy responsibility for taking their medication within the very strict guidelines provided by their doctors. These adolescents seemed to have a lot to worry about and support seemed to be important as a means of encouraging them, particularly on the more difficult days.

The participants also shared challenges that they experienced in relation to their clinics and health care providers. The experience at the hospital for most of the participants seemed to be tedious and overwhelming. A participant expressed being overwhelmed by the amount of information he is given at the hospital and that he gets confused at times. He also expressed his frustration that just when he is getting used to one ARV regime, then it is changed and he is confused about this and does not understand why his health care providers do this. Again, the importance of keeping adolescents fully informed was highlighted. However, it also seemed to be important that this providing of information is done at each adolescent's pace so that they fully understand what is happening and what is expected from them. There was also an issue around having to miss school for checkups, as they miss important things in class and there seemed to be a worry about falling behind at school. Missing school due to the illness causes larger "gaps" in their learning, and trying to make up work that they never learned and, or do not understand is quite overwhelming and frustrating (Fennell, Leitz & Fantauzzi, 2012). These findings correlate with the findings of this study that HIV has an impact on school performance and attendance, which could even be a hindrance for a successful and healthy future. Absenteeism and, or dropping out of school has been found to be a big problem and has far reaching implication on these children's lives both economically and health (Fennell, Leitz & Fantauzzi, 2012). Belzer et al. (2005) also found that some HIV positive adolescents drop out of school; a factor that was linked to poor adherence. The participants in the current study seemed to be invested in going to school which seemed to be related to a wish to be able to go far in their future. However it cannot be ignored that absenteeism and dropping out of school is linked to living with a chronic illness an issue which needs to be addressed. Fennell, Leitz and Fantauzzi

(2012) noted that managing and accommodating students with chronic illnesses is a big challenge for both the health and educational institutions but a need for understanding and assistance for these children by their teachers, health and educational systems is needed. This can be achieved on an individual level by the students and their family taking more initiative with their daily schedule and study time, collecting their homework or class requirements on the days of their clinic visits or away from school (Fennell, Leitz & Fantauzzi, 2012). On an institutional level teachers and education systems can take the initiatives to understand these students' condition and be able to educate them according to their abilities and needs such as with brain based learning: a system which assesses how one's brain learns and then allows for a variety of strategies to be applied (Fennell, Leitz & Fantauzzi, 2012). Support has to be available from all domains so these adolescents and children's future do not get further hindered by their illness.

The participants in this study were easily able to go for their medical checkups and they also had access to nutritious food at the shelter. One participant, however, did express that before moving to the shelter he did not eat as well as he should be eating. Several studies have also found that components of SES play a role in poor adherence issues associated with SES, such as the inability to afford transport fares, and food, which results in missed medical appointments and malnutrition (Amberbir et al., 2008; Ferrand et al., 2009). In the current study despite the support offered by the shelter, there were various factors that required time and routine that negatively influenced the participants' experiences of taking ARVs.

6.3.2. The stigma and fear of ARVs

The other major challenge that the participants experienced on a more social level was captured by this sub-theme. The issue of stigma and fear of ARVs was also strongly expressed by the participants. One participant expressed his dislike of going to the hospital as he is worried that people will find out that he is HIV positive. This seemed to indicate a fear of stigma. Another participant expressed the following about his fears about rejection if he was to reveal his status, which could also be likened to a fear of stigma. All the participants had a fear that if they were to reveal their status to their friends, they would be rejected. One participant described his fear of taking his ARVs in front of his HIV negative peers; he fears that they will make fun of him.

There also seemed to be a fear of what their peers might do if they were to find out about their status. Some participants seemed quite ambivalent about trusting their HIV negative friends, as even though they implied that their friends would accept their status, they still made a choice not to take the risk and disclose. It seemed that there is some hope that their friends would accept them but the risk of stigma and rejection is too big a risk to take, so they make the choice of concealing this part of themselves.

Some other participants were very clear about not trusting their friends enough to disclose their status, as they feared their friends could use that information against them. One participant was scared that once her friends knew about her HIV status they would ridicule her and refuse to play with her. This seemed to be a big concern for her: a fear of being rejected and not belonging. As discussed earlier due to adolescents need for identification with peers, this may feel too big. This fear of stigma was powerful and a real threat and in this case it correlates with the issue of identification for these adolescent participants. A fear of stigma does not just exist just with peers but also within families. One of the participants in this study shared that some of her siblings do not know about her status and this supported Campbell et al.'s (2005) findings that even within the nuclear family secrets and non-disclosure occurs. Campbell et al. (2005) found that some children were also afraid to even disclose their status to their own parents as they worried they would be stigmatised by them. The same study also found that some families would hide away sick relatives, depriving them of health care and support, or they disowned dead relatives and refused to go claim their bodies at the mortuary. It was also found that even sick relatives would not ever talk about having AIDS. Among the participants of this study, there was a lot of anxiety about disclosing their status to both close people and strangers and so a lot of secrets and lies seemed to be told to conceal the truth of their status. Secrets appeared to be an everyday part of their lives, as it was difficult for them to trust what others may do with the information. This fear seemed to be linked to awareness that HIV is associated with a stigma.

One participant made the following statement: "I take tablets for mentally something and stuff" (Tebogo). For this participant, it seemed that he would rather people think he has a mental disorder than for them to know he is HIV positive. This seemed to capture the extent of the issue

around shame and self stigma towards their status. A qualitative study in Uganda found that stigma was a barrier to ART adherence (Atuyambe et al., 2009); and internalised stigma has been identified as being associated with important health outcomes such as delays in pharmacy refills and medical care (Chirwa et al., 2008). Chirwa et al. (2008) study illustrated how if one experiences stigma in their immediate environment, then that can translate to how one views their own status, such as with self stigma. The participants in this study seemed to have internalised some of the stigma that they perceive exists in their communities, as they seemed not to trust that people such as friends or for some, even their teachers, would accept them. This seemed to reflect something about the participants themselves not having accepted their own status. Gibson and Rohleder (2005) found that the 'self' is continuously shaped through the prevailing social discourses and construction of meanings. Therefore, for an HIV positive person, whatever negative meanings or beliefs are adopted by their communities about HIV may be integrated into the construction of their self identities (Gibson & Rohleder, 2005). There seemed to be a real fear of rejection and along with that, a sense of shame and embarrassment around being HIV positive and taking ARVs, so various tactics were used by the participants to conceal their status and the reason for taking ARVs. One way was coming up with alternative reasons as to why they take medication and the other way was to hide the truth, such as not carrying their ARV prescriptions in their prescription bottles but rather keeping them in a neutral pill container so that they can continue to keep their status private.

6.3.3. Depression and loss and ARVs

One of the participants expressed his frustration with regard to going for checkups, as the doctors know when he is not adhering to his medication and they lecture him. This particular participant seemed to be really struggling with being HIV positive and taking medication. He seemed depressed and admitted that, at times, he does not adhere to his medication as he misses his late mother and sometimes he feels like he wants to stop his medication so that he can die and be with his mother. It was evident that in this adolescent's case, threats of death are not an effective means of motivating him to adhere to his medication. Many families have experienced the severe impact of HIV and AIDS. This was exactly what one of the participants felt when his mother died when he was 5 years old and he was moved from one home to another and only once he was

moved to the shelter, did he find some stability. The loss of his parents seemed still to be very painful for him, even now at the age of 17. Another participant also lost her mother to HIV, a fact at which she expressed being very angry and causing her to have anger management problems. Studies show that due to HIV, more and more children are being left orphaned and as a result they are bounced from one family member to another (Smit, 2010). The issue of mourning and loss was prevalent in these adolescents as they appeared to be mourning for lost loved ones and for an HIV negative life. The participants in this study have been infected and affected by HIV which is a very challenging and painful reality for them. Part of this reality was the challenge of being ill and having to miss school. One of the participants expressed how before starting her ARVs she was always sick and fell significantly behind at school, and although she is healthier now due to taking ARVs, she is still behind and struggling with school, unlike her classmates. This seemed to perpetuate her feeling that she does not fit in. There was also the issue of their treatment regimens being changed just as they were getting used to the previous regimen and this lack of stability seemed to be quite frustrating.

While some challenges were on a very personal level and some at a broader level, sometimes these frustrations lead to a contemplation of non-adherence or defaulting. Some of the participants shared that sometimes they do not want to take their medication so they lie to their caregivers and that they know of peers who lie and say they took their medication whilst they have not. Some participants shared the fact that sometimes they throw away their medication or that they know some of their friends throw away their medication. This seemed to suggest that the adolescents' moods influence their adherence to their medication; when depressed or preoccupied with worry, the motivation to take their ARVs seemed to decrease. This was similar to Belzer et al.'s (2005) finding that depression led to poor adherence. One participant expressed the following: "I like don't wanna take them, you feel so disgusted when they say medication...for me, sometimes, I feel like, it says just run away or hide" (Tshepo). There was a sense that him feeling sickened by his medication may have been related to his anger and hate towards being HIV positive and having to take medication and a wish to escape. However the participants also experienced disadvantages when not adhering, as they would get into a lot of trouble and on a more serious level, get ill when they did not adhere to their medication, which

would then motivate them to get back on their regime. This section highlighted how difficult it can sometimes be for these adolescents and how, at times, they really struggle with living with HIV and having to take ARVs. There seemed to be a lot of anger, and at times, pain and depression due to these challenges, leading to a sense of helplessness and hopelessness, which in turn led to them wanting to default or, at times, actually not adhering to their ARVs.

6.3.4. ARVs complicating normal adolescent developmental challenges

The psychosocial approach indicates that there are five main sets of developmental issues during adolescence: identity, autonomy, intimacy, sexuality and achievement (Steinberg, 2005). While adolescence is normally associated with growing independence, these adolescents' need for medication and having to rely on others to make decisions around their medication made striving for independence more difficult, which was frustrating for the participants. The participants also spoke about having experienced other challenges, some of which were directly linked to their experience of taking ARVs and some related to social challenges. The challenges they face appeared to be developmental and life challenges common to all adolescents, however, these challenges seem to be more difficult in relation to being HIV positive and taking ARVs. This included negative peer pressure, unstable family backgrounds and for some, mourning the loss of their mothers. Two of the participants described how they have been subject to peer pressure to drink and the difficulty associated with this due to the importance of them avoiding such situations. Alcohol use is been found to influence adherence (Belzer et.al, 2005). Alcohol and drug abuse is also quite prevalent amongst adolescents in South Africa (Peltzer & Ramlagan, 2009; Reddy et al., 2010), but for adolescents with HIV, who have been counselled as to the health risks of drinking and smoking, this pressure seemed to feel more threatening. Adherence is a treatment process and a life style where the patient has to be an active member in that process; health care providers believe that it is more than taking one's medication but that it is also about following a diet and, or executing lifestyle changes (WHO, 2003). This includes not abusing alcohol, as this does not mix well with the ART. These adolescents have to be able to take responsibility for their lives and choose to go against what their friends are doing despite the possible consequence of being rejected. Blos (as cited in Balk, 1995) stated that adolescents try to form new ego ideals that are separate from dependency on parents, form more heterosexual

relationships and develop a mature identity; and that failure to achieve these ego ideals can result in a permanent barrier to maturity. The forming of these ego ideals may be particularly hard for adolescents living with HIV because as well as trying to cope with the normal challenges of identity formation in adolescence and fitting in; they are also trying to find ways to cope with an HIV positive identity and make responsible choices instead of experimenting as their friends are. One of the participants even described the dangers for him to just sleep in when he does not have school, as there is the risk of him missing his medication. Another concern was being away from home, such as going away for camp and having to worry about where to hide their medication. Alongside this fear there seemed to be a concern around others finding out that they are on ARVs which aroused a fear of rejection. The challenges that these adolescents have to worry about suggested that they cannot be as care free as their HIV negative peers.

6.4. The factors that help adolescents adhere to their antiretroviral (ARV) medication

The participants also named a number of factors that help them to adhere to their ARVs. These factors are best illustrated by the sub-themes: understanding and awareness; support, practical strategies; emotional defence mechanisms and the process of acceptance.

6.4.1. Understanding and awareness

The process of coming to fully understand and acknowledge the purpose and importance of ART and having a positive attitude towards the medication and adherence seemed to play significant roles in the coping of these adolescents. This was illustrated in the 'Help (good meds and trusted others)' sub-theme which was identified in the analysis. Their process of meaning making and awareness enabled the participants to overcome the challenges that they experience with taking and adhering to the medication. The following quote from one of the participants really captured how holding on to the positive aspects of what ARVs can do helps with adherence: "Taking my meds is a big role in my life, cause without that medicine I'd be like okay, suffering and stuff in the hospitals, yah fighting for my life... What I understand is that they help you, they help you reach your goals, reach anywhere you want to be, because without life there is nothing" (Tebogo). This quote illustrated the more positive experiences with their ARVs. The participants appeared to have experienced for themselves that adhering to their ARVs improves their health

as they do not get sick often as before and instead have gained weight, and have more energy. A study done in Tanzania also found that patients' confidence in ARVs after experiencing improvements in their health facilitates adherence. This was what the current research also found, as improved health seemed to give the participants some sense of normality as they can now properly attend school, catch up with their school work and be more like their HIV negative peers which is important to them. Holding onto the idea that the ARVs give them life seemed to assist the adolescents to have hope in a future, in which they can meet their goals and have a long life to be with their families. One of the participants reflected a fantasy to be able to cure HIV and the medication seemed to be linked in his mind to a hope and sense of a future. Another participant reflected a positive outlook on their experience of the ARVs and holding onto the belief that the ARVs give life. These beliefs seemed to facilitate adherence for them, particularly during the difficult times when they feel angry and frustrated and do not want to adhere to their ARVs.

6.4.2. Support

A positive hospital experience, such as being around other children who are having similar experiences also appeared to help and possibly added to a sense of belonging, instead of feeling alone, as if they are the only ones living like this. One of the participants expressed the following hospital experience: "It's like everyone is taking it just like me. Yes... It makes me feel better because I saw lots of people taking, fetch their ARVs" (Pule). Another participant described that there is a support group for adolescents at the hospital where he is able to interact and have fun with other adolescents who are taking ARVs. This seemed to improve the hospital experience and makes it a less dreadful place. It also seemed that having a good, open, supportive and trustworthy relationship with their doctor really encouraged the adolescents to adhere to their medication. Research shows that people who have a good relationship with their health provider were better able to communicate and were more likely to adhere (Murphy et al., 2004). Murphy et al.'s (2004) study found that the more patients trusted and believed in what their health provider was saying, the more likely that they would listen and adhere to their medication. A study in Brazil presented similar findings: that adherence was associated to the relationship patients had with the health care workers (Abreu et al., 2008). A South African study also

confirmed the importance of disclosure, having social support and a strong belief in the value of treatment, as these were found to facilitate adherence (Dahab et al., 2008). It seemed that having trust in their doctor also encouraged the adolescents to believe in and trust the ARVs, as they described feeling a sense of security that their doctor has their best interest at heart.

Along with having a good relationship with their doctor it seemed that having supportive, trusted others really facilitated the adolescents' coping with taking medication and adherence. The participants expressed being happy to have someone they can trust and depend on who reminds them to take their medication and makes sure that they take their medication. One participant expressed feeling safe as her trusted caregivers do not only help her manage the taking of medication but they also keep her safe from catching infections which could jeopardise her health. The participants also expressed how these trusted others are also able to explain to them and advise them on how to take their medication. A study conducted in Los Angeles was also supported by the findings of the current study in that both studies found that social support and professional support facilitate ARV adherence (Roberts, 2000). As the participants live in a shelter with other adolescents who are on ARVs, they also seemed to support each other. They seemed to help each other to manage their ART by waking each other up in the mornings, reminding each other and also following up on each other when they notice that one of them is not adhering to their medication. Watt et al.'s (2009) study also found that material support, such as food and money and emotional support from family, friends, counsellors and their health care providers assists with adherence. The participants in the current study seemed to indicate that they have lots of support adhering to their medication, both when they are at the shelter and also when they are away visiting their families. However they also have strategies that they employ themselves to remind themselves to take their medication.

6.4.3. Practical strategies

There were various strategies employed in the management of ART in this study and one of the participants expressed paying attention to the clock when he is at home when he knows it is almost medication time, which seemed to highlight the process of routinising. Watt et al. (2009) emphasised that routinising the taking of medication by linking it with day to day activities can

help individuals to remember to take their medication. Another participant shared that when she does not have anyone around to remind her she sets an alarm on her cellular phone as a reminder to her. Roberts' (2000) research found that there are various strategies employed by HIV positive people to help with adherence such as making a commitment, routinising, medi-sets, alarm clocks, written notes and day planners, which can remove the burden of having to remember complex medication schedules which are common to ARV regimens. However some people are concerned that there may be some stigma associated with using the medi-sets (Roberts, 2000). This was also evident in this study, as one participant shared that he preferred to keep his medication in a neutral container when he is away from the shelter instead of the original ARV medication bottles so that people will not know what medication he is taking. There were times when the participants take responsibility for their medication, however, giving responsibility to adolescents has to be done in moderation as Farley et al.'s (2006) study identified that older adolescents have an increased likelihood of non-adherence, and thus caregivers must be careful with regards to giving adolescents too much responsibility too early. Farley et al.'s (2006) study found that the responsibility of medication adherence may be premature for some adolescents, given that HIV infection may have caused cognitive or emotional difficulties that may influence their ability to function independently, unlike their HIV negative age mates.

6.4.4. Emotional defence mechanisms

Along with the participants having positive beliefs about their medication and also having supportive structures to help them cope and manage with the difficult task of adhering to their medication amidst all the challenges they face, they have also adopted various defences. These help them cope with the difficulties of being an HIV positive adolescent who has to take medication every day while their peers do not. Finding out about their HIV positive status seemed to be quite traumatic for the participants and some described going through a period of denial from the shock of finding out their HIV positive status, which appeared to be the first step of bereavement (Kubler-Ross, 1970). Trying to cope with their terminal diagnosis seems to have led the adolescents in this study to employ a more paranoid schizoid way of functioning, in which primitive defences, such as denial of inner and outer reality, stifling of emotions, splitting and projection were used (Klein, 1946). The discovery of an HIV positive status seemed to be

experienced as a loss and sometimes this loss was too much for the adolescents to handle and thus many of them appeared to use the primitive defence mechanism of denial. Although at the stage that this study was conducted it was clear that all of the participants had passed through the stage of denial, it was clear that many of the participants were still engaged in a mourning process, attempting to come to terms with their diagnosis. The different stages of bereavement are negotiated for differing times by various individuals, and they can also follow one after the other or coincide (Kubler-Ross, 1970). The participants in this study seemed to describe experiences in which sometimes they get very frustrated and angry about being HIV positive and having to take medication and worry about adhering to medication, however, they also described at other times being in a state of depression. They seemed to move in between these two states. While these two stages appear to resemble Kubler-Ross' (1970) stages of anger and depression, it is, however, also important to note that in adolescence depression can be masked by anger (Sadock & Sadock, 2007). This means that depression would present with more irritability and frustration rather than a depressed mood.

The use of manic defences was also evident in the participants in this study. The following extract illustrated the use of a manic defence (Lemma, 2003), where instead of the seriousness of not adhering to ones medication being acknowledged, it was avoided and instead humour was used: "Yah I feel safe because he is the only one who knows and stuff, he not gonna do like, okay, you gonna die by HIV and stuff. Okay we all make jokes, yah we all make jokes but you must drink your medication. I tell him why? It's obvious you already know, why you asking and we laugh and laugh and you drink" (Tebogo). In this instance there seemed to be some avoidance of talking about the more serious implications of not taking ARVs, but instead the frustrations and worry was engaged with in a more playful way. Manic defences are also primitive defences which aim to deny depressive anxiety and guilt (Lemma, 2003), which was illustrated by the participant. The participants seemed to also be using splitting as a defence mechanism. This was evident in their descriptions of times when they feel that the medication is all bad and other times when they feel that the medication is all good. There also seemed to be a splitting of people in their lives: those whom they can trust with their status and those whom they cannot trust. Even during the interview there seemed to be a process of splitting. There were notable

inconsistencies and contradictions in their accounts of their experiences, as at times they would report everything being fine but as they elaborated further it became clear that they also experience a lot of challenges and adversities around being HIV positive and adhering to medication. This defence is a way of splitting off knowledge about one part of the personality or experience under the pressure of anxiety and guilt; and is most often used in order to keep two usually opposing feelings or thoughts separate (Klein, 1946; Lemma, 2003). It seemed that the participants' need to split off the parts of themselves and their experience that they find intolerable, such as the parts of themselves that do not want to adhere to their medication and parts of themselves that actually do not adhere. This seemed to allow them to be able to cope with their anxieties of not adhering to their medication or the contemplation to do so, particularly as they are very aware of what not adhering to their medication means. This illustrated the use of primitive defence mechanisms being used by the participants as a way of coping and managing with the difficulties of having to live with HIV and take medication at a specific time, every day of their lives.

Although in the current study certain primitive defences were used, there were also some neurotic defences being used. One participant described using reaction formation. This is when someone transforms a disturbing idea into its opposite (Lemma, 2003). In this case one of the participants described feeling no different to his HIV negative peers and seemed very invested in maintaining this belief. It seemed that through the use of a reaction formation defence he was able to avoid confronting what felt different between him and his peers and what may leave him feeling isolated. Another example of a more neurotic defence being used was that of repression (Lemma, 2003), where one of the participants spoke about how when he goes to the hospital they sometimes find that he is not adhering well to his medication, but when he was asked how often this happens he said that he does not remember, which could be an indication of him repressing the memory as it is too anxiety provoking and difficult for him to acknowledge and hold in mind. It seemed that depending on where the adolescent is in the process of trying to accept their illness determined the defences that they employ to help them cope with the more difficult emotions of their experience. Pedersen and Elklit's (1995) study, also found that their participants relied more on neurotic defences than the primitive defences, particularly in relation

to anxiety. It seems that in this study the participants were not at a place of full acceptance of their status, so they tended to fluctuate and adopt various defence mechanisms depending on what their experience provoked.

6.4.5. The process of acceptance

As discussed above, the adolescents in this study were not at a place of full acceptance. It is also important to acknowledge that due to their developmental stage and where they are cognitively, they may be unable to come to a state of full acceptance of their status and the reality that they have to take ARVs for the rest of their lives (Farley et al., 2006). However, it seemed that there was some process of acceptance occurring, which was one of the predominant themes found in the study. This theme highlighted the way in which the participants in this study make sense of being HIV positive and having to take ARVs every day for the rest of their lives. The first issue that was evident was the process of trying to obtain full disclosure about how they were infected, as the participants who did not know how they got HIV seemed much invested in finding out that information. It seemed that as mentioned earlier having full disclosure and being allowed the space to ask their questions was important. Kubler-Ross (1970) talks of the last stage of bereavement as that of acceptance, in which individuals do not harbour any anger or depression, but rather are almost void of emotion about their fate. However, Kubler-Ross (1970) studied individuals with terminal illnesses, all of whom did eventually die. HIV appears to be different, in that although terminal, it is an illness that can be managed with ARVs for extended periods of time. Thus, acceptance as being devoid of emotion and resigned to the fate of death does not apply here. Acceptance in the case of HIV seems to mean finding a way to live with an illness and all its physical and emotional consequences. The participants in this study were not at this point as yet; but anger, frustration and depression, particularly for those who did not know how they were infected with HIV, were prevalent emotions. It seemed that, that not having full disclosure of their status contributed to the challenges of accepting their status. It was almost as if they felt there is a big piece of the puzzle of their life missing and that until the puzzle piece is found, it is difficult to move forward and instead there is a lot of frustration, anger, a deep sadness, helplessness and desperation involved in coming to terms with ones HIV positive status. These feelings seemed to be managed through lots of enquiry and knowledge being gained about

how one can get infected with HIV, which appeared to help with their understanding of the HIV virus. This once again highlighted the earlier point of the importance of full disclosure.

There was also a process of reasoning and a need to let go of the focus on how they were infected, and rather focus more on the present, which was the reality that they will have to live with HIV for the rest of their lives. One of the participants described initially feeling resentful and wanting to 'stuff HIV!' but through his processing of these feelings and watching 'Soul Budz' (a children's show that deals with issues of HIV and AIDS), he described learning that HIV is not a death sentence and that one can live with it and this understanding helped him in his process of trying to get used to his ARVs. Research has shown that emotional regulation is vital in the process of psychological adjustment which is vital for living with a chronic illness (Ridder, Geenen, Kuijer, Van Middendorp, 2008). Hope in a future and meeting ones dreams and having a purpose seemed also to have helped with the process of taking their ARVs. Some of the participants expressed wanting to be able to live with and help their families, which for them facilitated the process of acceptance and adhering to their ARVs. One of the participants described how seeing his ARVs as any other tablet, such as the ones he was taking before (possibly vitamins) helped him manage taking his ARVs, instead of viewing them as a burden. While this may also be an avoidance of the reality that the tablets are for his HIV, this way of thinking appeared to facilitate his adherence to his medication. Another participant expressed how focusing on the benefits of the ARVs, such as being healthy, helps with adherence. Studies have found that benefit finding once diagnosed with a chronic illness can help with psychological adjustment and living with chronic illness (Ridder, Geenen, Kuijer, Van Middendorp, 2008). This indicates that it can bring benefits and improvements in our attitude to life and the way we live our lives for the better. It also seemed that with time the participants have become used to taking the ARVs and have found similarities with their HIV negative peers. This process of identification with peers appeared to assist in the process of acceptance of being HIV positive and having to take ARVs. This was also linked to a process of moving away from shame about ones HIV status. Most of the participants illustrated various processes of meaning making and most of them seemed to try to focus more on the positive factors of ARVs, which appeared to help them accept their HIV status and a life of having to take medication every day.

One of the participants, however, seemed to be at the early stages of this process of acceptance, as she was the only one out of all the participants who had recently found out about her status and also had only been taking ARVs for a few months, so she was still trying to grapple with a lot of the raw emotion evoked by disclosure. This suggested that time is a very important contributing factor in how the adolescents work through the more difficult feelings and that time also allowed for the development of coping mechanisms. It seemed that with time they are able to get used to their new lifestyle of taking ARVs and some were even able to shift from a space of feeling alone and at risk of rejection, to being able to identify with their HIV negative counterparts. Chronic illness can also bring an improved appreciation of life, an enhanced sense of purpose, changes in life priorities, and improved personal relationships (Ridder, Geenen, Kuijer, Van Middendorp, 2008). However it is important to be aware that this is a process and can take time. It is also very important to also be aware when this process takes place as if it is during the earlier phase of diagnosis it may indicate denial.

6.5. Conclusion

In this chapter the discussion was focused on the HIV positive adolescents' experiences with ART adherence. It highlighted the importance of disclosure, their struggle to develop an identity that integrates their HIV positive status, and that taking ARVs was choosing to live. The challenges that these adolescents experience in adhering to their ARV medication was also discussed in relation to the challenges to adherence, which has also been found in other studies. These challenges included: the inconvenience of ARVs; the stigma and fear of ARVs; depression and loss and ARVs; and ARVs complicating normal adolescent developmental challenges. Lastly, the factors that assist these adolescents to adhere to their antiretroviral (ARV) medication were discussed. The importance of understanding and awareness, support, practical strategies, emotional defence mechanisms, and the process of acceptance were highlighted. These were also discussed in relation to similar studies on this and related topics. This chapter also discussed the research findings in relation to various developmental theories which allowed for a better understanding and conceptualisation of what these adolescents are experiencing daily, the challenges they are faced with when it comes to adherence and also the things that help them to adhere.

Chapter 7: Conclusion

7.1. Summary of research findings

The aim of this study was to examine the experiences of adolescents who are HIV positive with regard to their experience of adherence to their ARVs. This study focused on the experiences of 5 South African HIV positive adolescents' who live in a shelter for homeless HIV positive women and children. Their experiences with ART adherence was explored in relation to the factors that help them adhere to their ARV medication and the challenges that they experience in adhering to their ARV medication. The researcher conducted five semi-structured interviews with HIV positive adolescents from two homes belonging to a shelter in Johannesburg. These interviews generated some rich, very informative data with regard to adolescents' experiences living with HIV and having to adhere to ARVs. This research confirmed and substantiated a number of the findings that emerged from previous studies regarding the challenges and the supportive factors experienced by adolescents living with HIV and adhering to ARVs. The numerous factors that form part of these adolescents' experiences of adherence are as follows:

- The first issue that arose in all the interviews was that of the importance of the adolescents being disclosed to with regard to their HIV positive status and the reason for taking ARVs. Knowing their HIV status seemed to help these adolescents understand what HIV is and the importance of adhering to their ARVs. This also allowed them to make meaning and start a process of acceptance of their status and the importance of adherence. The importance of disclosure was well highlighted and coincides with other studies which have highlighted the importance of disclosure to children (Vaz et al., 2010).
- Disclosure of their HIV status brought awareness; however, it also necessitated a fairly stressful process of incorporating an HIV positive diagnosis into their developing identities. The formation of a stable sense of identity is a very important task of adolescence. It seemed that the participants struggled with this process, grappling with how to incorporate their HIV positive status into their still forming identities. Being HIV positive seemed to carry the concept of difference, which sometimes seemed to make it difficult for these adolescents to feel like they fit in with their HIV negative peers. Most of the participants in this study felt

like they were different from their HIV negative counterparts, which seemed to disrupt this developmental stage of an increased identification with their peers.

- Linked to identification with peers was also the fear of stigma. This research study also found that adolescents are faced with the challenge that their peers will reject or make fun of them if they were to know of their HIV positive status. Due to this fear of stigma the participants in this study tended to conceal their status and hide or disguise the taking of their ARVs, particularly if they were away from home. They also tended to conceal the truth regarding the nature of their medication, whenever someone saw their ARVs. This part or their lives seemed to be kept secret from friends and, or family.
- There was also a very strong theme of the issue of life or death. This study indicated that being HIV positive for these adolescents carried a possibility of death and adhering to medication meant choosing to live and fighting death. It seemed that when these adolescents take their medication every day, they are faced with the issue of life or death, as for them adherence means choosing life and not adhering means choosing death.

This study also highlighted some of the challenges that these participants face daily, which sometimes have an influence on their levels of adherence. These challenges included the following issues:

- The inconveniences of adherence were noted by the participants, such as: side effects from the medication, having to maintain strict time requirements, having to take ARVs everyday for the rest of their lives, waking up early to take ARVs, and disruption to their leisure time.
- Negative experiences at the hospital when they go for their regular checkups were also mentioned as being a deterrent. These included: a fear of stigma, being overwhelmed by the amount of information given, the burden of the ARV regime being changed, and having to miss school for checkups which raised the concern that they will fall behind at school.
- Negative peer pressure from friends around drinking and smoking was also cited as a challenge and something that adds complications to adherence.
- It also seemed that the participants had experienced many losses, such as the loss of loved ones and also the loss of being HIV negative. They seemed to experience depression around

these losses, which they reported as having a significant influence on their levels of non-adherence. For the most part, it seemed that this depression and related non-adherence was concealed from their parents or guardians.

The study also indicated factors that facilitate adherence for these adolescents, which are as follows:

- Understanding and awareness of the purpose of ARVs seemed to facilitate adherence and this was linked to the issue of disclosure.
- Having a good support system and trusting parents or guardians, peers who are HIV positive and their health care providers seemed to help with the burdens and challenges experienced with ART.
- A positive hospital experience and a good relationship with their health care provider were highlighted as aiding with adherence.
- A positive attitude towards the medication and certain emotional defence mechanisms that the adolescents employed seemed also to lighten the burden experienced with taking ARVs every day.
- This study also highlighted that although these adolescents seem not to have reached full acceptance of their status, they were all in various stages of the process of acceptance.

7.2. Recommendations

The current research study had some strengths. Due to the qualitative nature of the study and the use of a holistic theoretical framework, the research study was able to attain a wealth of information about the experiences of these particular HIV positive adolescents. In particular, this research aimed to examine the unique experiences of adolescents on antiretroviral therapy (ART), in order to understand what helps them to adhere to their medication and the challenges that they may have with adherence. Since very little research has been done on this topic in South Africa, this study may provide an important starting point for future research in this area of study within the South African context. Future research could perhaps also include a more inclusive conceptualisation of adherence. The current study focused on whether the adolescents

are taking their medication as per advised by their health care provider. However as illustrated earlier adherence is also about a life style which is also about following a diet, and, or executing lifestyle changes (WHO, 2003), to better improve one's health. The findings of this study may also contribute to informing ways in which to assist adolescents to cope with living with HIV and adhering to ARVs, as this seems to be quite challenging for these individuals. An understanding that openness with regards to disclosure and time for processing assists these adolescents may help caregivers to provide appropriate support. This study may also inform recommendations for how to work with and support adolescents in South Africa to manage the burdens and challenges related to ART and adherence.

As identified in this study a positive experience at the hospital is facilitative for adherence, as it is linked to adolescents being able to communicate their challenges to their health care providers. Health care providers can provide a more supportive role for adolescents and their caregivers. They can make sure that they tailor their care and services to suit adolescents by creating a friendly environment that allows the adolescents to be comfortable and feel free to raise concerns with their health care provider. They could also modify the way in which and pace at which information is given, which would increase awareness and allow the adolescents to feel comfortable to be open and ask questions and engage in conversation about what they are experiencing, rather than feeling overwhelmed and, or dreading to go for follow up appointments. This will also provide them with the right information about their medication and diagnosis. It also seems from this study that full disclosure is very important as it facilitates the process of acceptance. It seems to be important that this is done carefully, and perhaps health care providers can collaborate with caregivers to assist with this process. The health care providers can also provide the adolescents with psychosocial support to allow them to express themselves on their follow up appointments. Along with this they could also provide support groups where adolescents can interact with their peers and share their experiences and share their coping mechanisms which help them to adjust to being HIV positive and being on ARVs. Such a space may allow for adolescents to be able to identify with their peers instead of feeling different, which is an important developmental factor in adolescence.

In this study the theme of death was very strong and it appears that when adolescents are informed of the purpose of being on ART and the importance of adherence, the theme of death is strongly enforced. This may be psychologically harmful as the adolescents seem to then live in a state of fear that if they do not adhere they may die. Living in a state of continuously thinking of the possibility of death may have a negative effect and certain adolescents may give up on a belief that they can live a long life with HIV and instead lose hope and give up. It is important that heath care providers and caregivers promote life and are more positive in their teachings of the importance of adherence so that these adolescents can have a more positive outlook on their lives and be encouraged to adhere to their medication and be healthy, instead of feeling overwhelmed by a fear of death and giving up on life.

7.3. Limitations

The current study also had some limitations. The first and most important thing to note is that this research study was an exploratory study by nature with a limited scope given the constraints of the Masters year. Thus, this study had a very small sample size. This was also the result of difficulties finding adolescents willing to participate in the study. This prevents the research findings being generalisable to the rest of the population of HIV positive adolescents on ARVs in South Africa. Due to time constraints and practical reasons this research study only focused on children living in a shelter instead of a more diverse population, which also affects generalisability of the findings. This also is problematic as it appears that the adolescents in the shelter have a lot of support and monitoring when it comes to ART, making it easier for them to adhere to their ARVs. This may be unlike the rest of this population of HIV positive adolescents on ARVs, as for adolescents living in less sheltered environments; support and monitoring may not always be a reality. It would thus be very important to explore further the experiences of adolescents who do not live in a shelter or get as much support and how they are able to cope and overcome their challenges. This may generate different data. Another limitation to this study is that it focused on one aspect of adherence which was the medical definition to adherence and this may have limited our scope of exploration as there are more elaborate factors which can be considered with adherence of ARVs which were not captured in this study, such as following strict dietary plans and change in life style to accommodate ART requirements for adherence.

Further research in this crucial area would deepen our understandings around what HIV positive adolescents are experiencing, so that policies can be drawn to assist and support them to increase and maintain adherence.

7.4. Conclusion

This study has highlighted the experiences of five HIV positive adolescents with regard to being on ARVs and following strict routines to ensure adherence. The participants in this study were very open around their experiences of adherence to ARVs and how challenging it can be for both themselves and their peers who are also taking ARVs. This study also confirmed that non-adherence is a real problem. However the study also provided information as to the factors that assist with adherence, which have been noted above. The current study had both strengths and weaknesses; however a wealth of knowledge was obtained, allowing for a better understanding of what these particular adolescents experience in relation to adhering to ARVs. This research was a starting point for further research to be conducted on the experiences of HIV positive adolescents with regards to adherence to ARVs, which may inform policies to better assist and support this booming population.

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Appendix A
Letter to Shelter Director

School of Human and Community Development
Private Bag 3, Wits 2050, Johannesburg, South Africa
Tel: (011) 717- 4500 Fax: (011) 717-4559

Dear Ms. Heather Snyman

My name is Natasha Maswikiti. I am a student at the University of the Witwatersrand studying Clinical psychology. I would like your permission to conduct research as part of my research project at a shelter in Johannesburg. I am interested in interviewing 8 adolescents between the ages of 12 and 16 years living with HIV on antiretroviral therapy. If your permission to conduct the study at the shelter is granted, a meeting will be set up to meet the adolescents at the shelter and explain the aims of the research and the criteria of participants needed. The potential participants will be invited to participate and the individual interviews will be run on-site at the shelter. In-depth interviews will be conducted and an mp3 recorder will be used to record the interviews. Interviews are estimated to last approximately 1 hour and regular breaks will be given if needed. The interviews will be audio recorded, however only the researcher and research supervisor will have access to them. The transcripts and the final report will not contain any identifying information of the adolescents involved in the study and as such their rights to confidentiality and anonymity will be respected. Participants and their parents/ guardian will be asked to give their informed consent in this regard. After the research is finished the adolescent's recordings and transcripts will be kept in password-protected file on a computer for 2 years if the study is published or 6 years if it is not published before it is destroyed. All participants will have the right not to answer any questions they may not wish to answer and to discontinue their participation in the study at any time. The aim of this research project is to explore the experiences of adolescents on antiretroviral therapy (ART), in order to understand their thoughts, feelings and behaviours around ART and the challenges they may have with adherence.

On completion of the research you will be informed of the findings through a letter. The contact details of myself and my supervisor are attached to this form in the event that you may have any further questions or concerns.

Kind regards

Natasha Maswikiti

Phone: 082 849 5326

Email: tashamas@gmail.com

Dr Katherine bain (supervisor)

011 717 4558

Email: katherine.bain@wits.ac.za

Appendix B

Participant Information Sheet - parent/guardian

Hello.

My name is Natasha Maswikiti. I am studying a Masters degree in Clinical Psychology at the University of the Witwatersrand. I would like your permission to conduct research as part of my degree and am inviting your child to take part in a research study. My project is on South African adolescents experience with antiretroviral treatment (ART) adherence. The purpose of this research project is to have a better understanding of adolescents experience with ART adherence and possibly find ways in which to support and help them and their peers adhere to ART.

Taking part in the study would mean they would be interviewed about their personal experience, understanding and feelings around being on ART and adhering to it. The interviews will take place at the shelter and would happen in a private room. The interview will take about an hour, but the researcher will make sure that she/he rests if she/he gets tired. Your child can choose not to answer any questions that she/he does not want to, there are no right or wrong answers and she/he may stop the interview at any time. Choosing to be part of this research is up to you and your child. Being a part of the interview can help us understand your child and her/his peers better, but during the interview things may come up that may make your child sad. If this happens and your child feels like she/he needs to speak to someone after the interview, the researcher can arrange counselling for your child at the shelter.

If you and your child decide to take part in the research, the interview will be tape recorded and the researcher and the research supervisor will know who your child is, but both of us promise to keep you and your child's identity and information private. Researcher will write up your child's interview (transcript) and all her/his identifying information will be removed from it. Then the researcher will see it together with the research supervisor from the University of Witwatersrand. The audio recordings and the transcripts will be kept in a locked cupboard in the researcher's office or on her computer which has a password so only she can see the information. Quotes using your child's words will be used in the report, however, no identifying information will be included and they will be used with quotes from other interviews. After the report is finished the interview recordings and transcripts will be kept in secure places for 2 years if the research is published in a journal or for 6 years if it is not published, before it is destroyed. General feedback will be given in the form of a letter to the Director of the shelter and the finished report will be seen by the public. Feedback can also be given to you in the form of a letter and if you would like more feedback I will give it to you with pleasure. My contact details are attached to this form.

If you do choose to participate please can you fill out the two consent forms attached and give them back to me; the one is consent for your child to participate and the other is consent for the audio recording.

Please feel free to contact either me if you would like any further information, have any further questions, or would like to report any negative affects the study has had on your child.

Kind regards

Natasha Maswikiti

(Researcher)

Email: tashamas@gmail.com

If you would like to report any problems or complaints that you have with regard to any part of the research process you can also contact the University of the Witwatersrand's Human Research Ethics Committee Secretary on (011) 717 1252.

Appendix C

Consent Form (Interview, and research participation) – parent/guardian

I _____ consent to my child/ward (child's name) _____being interviewed for the purposes of a research project looking at antiretroviral treatment adherence in adolescents in South Africa being conducted by Natasha Maswikiti. I understand that:

- Participation in this research is voluntary.
- My child has the choice to not answer any questions she/he does not want to answer.
- My child may stop participating at any time.
- Direct quotes (the words my child uses) will be used in the report, however, no personal information that may identify my child will be included in the report, and my child's responses will remain confidential.
- During the interview your child may disclose complicated feelings around their status and taking medication, if this is the case and they are at risk of harming themselves or others at the end of the interview we will think about other ways to explore these feelings
- If during the research the researcher finds out something about my child which is harmful to them the researcher has the responsibility and my permission to report this to the necessary person at the centre who can help my child.
- After the report is finished, it will be made available to the Director at the shelter. I can request a summary of the findings if I am interested.
- The transcripts will be kept safely in a password-protected file on my computer for 2 years if the study is published or for 6 years if it is not published and then they will be destroyed.
- There are no anticipated risks for my child participating in this study, but if my child feels upset at any time they will be referred for free counselling .

Signed _____

Date _____

Appendix D

Consent Form (Audio Recording)-parent/guardian

I _____ consent for the interview that my child/ward _____ will have with Natasha Maswikiti to be tape recorded. I understand that:

- The tape and transcript (these are written documents which contain what has been said in the interview) will not be heard or seen by any people other than the researcher and her research supervisor, who will keep what my child said private.
- The recordings will be heard by the researcher and the research supervisor only.
- No personal information, such as names (yours, your child, your family etc.) or places (where you live, where you are from etc.) will be used in the transcripts or the report.
- After the report is finished my interview recording and transcript will be kept in a safe place that only the researcher will have access to for six years if no articles are published or two years if an article is published.

Signed _____

Date _____

Appendix E

Participant Information Sheet - participant (12-16)

Hello.

My name is Natasha Maswikiti. I am studying a Masters degree in Clinical Psychology at the University of the Witwatersrand. I am conducting research as part of my degree and I am inviting you to take part in this research project. My project is on South African adolescents experience with antiretroviral treatment (ART) adherence. The reason for doing this research project is to help us learn more about what HIV positive adolescents are experiencing with adhering to ART.

Taking part in the study would mean you would be interviewed on personal questions about what you understand, think, feel and experience with taking ART and adhering to it. The interview will be at the shelter and would happen in a private room. The interview will take about an hour, but the researcher will make sure that you take a break if you get tired. You can choose not to answer any questions that you do not want to, there are no right or wrong answers. You can say okay now and change your mind later. All you have to do is tell us you want to stop. No one will be mad at you if you don't want to be in the study or if you join the study and change your mind later and stop. Being a part of the interview can help us understand you and your peers better, but during the interview things may come up that may make you sad. If this happens and you feel like you need to speak to someone after the interview, the researcher can organise counselling for you at the shelter.

If you choose to take part in this research, the interview will be audio recorded and the researcher and the research supervisor from the University of Witwatersrand will know who you are, but both of us promise to keep your identity and information private. The researcher will write up your interview (transcript) and all your identifying information will be removed from it. Then the researcher will see it together with the research supervisor. The audio recordings and the transcripts will be kept in a locked cupboard in the researcher's office or on her computer which has a password so only she can see the information. Quotes using your exact words will be used in the report, however, no identifying information will be included and they will be used with exact words from your peers who will be in the study. After the report is finished the interview recordings and transcripts will be kept in safe place for 2 years if the research is published in a journal or for 6 years if it is not published, before it is destroyed. General feedback will be given in the form of a letter to the Director of the shelter and the finished report will be seen by the public. Feedback can also be given to you in the form of a letter and if you would like more feedback I will give it to you with pleasure. My contact details are attached to this form.

If you do choose to participate please can you fill out the two assent forms attached and give them back to me; the one is assent for you to participate and the other is assent for the audio recording.

If you join the study please feel free to contact either me if you would like any further information, I will answer any questions you have, and you can ask questions at any time. Just tell the researcher that you have a question.

Kind regards

Natasha Maswikiti

(Researcher)

Email: tashamas@gmail.com

If you would like to report any problems or complaints that you have with regard to any part of the research process you can also contact the University of the Witwatersrand's Human Research Ethics Committee Secretary on (011) 717 1252.

Appendix F

Assent Form (Interview, and research participation) – participant (12-16)

I _____ consent to being interviewed in for the purposes of a research project looking at Antiretroviral treatment adherence in adolescents in South Africa being conducted by Natasha Maswikiti. I understand that:

- Participation in this research is voluntary.
- I have the choice to not answer any questions I do not want to answer.
- I may stop participating at any time.
- Direct quotes will be used in the report, however, no personal information that may identify me will be included in the report, and my responses will remain confidential.
- During the interview you may disclose complicated feelings around your status and taking medication, if this is the case and you are at risk of harming yourself or others at the end of the interview we will think about other ways to explore these feelings.
- If during the research the researcher finds out something about me which is harmful to me they have the responsibility and permission to report this to the necessary person at the centre who can help me.
- After the report is finished, a copy will be given to the Director at the shelter.
- The transcripts will be kept safely in a password-protected file on my computer for 2 years if the study is published or for 6 years if it is not published and then they will be destroyed.
- There are no anticipated risks for me participating in this study, but if I feel upset at any time I can be referred for individual counselling.

Signed _____

Date _____

Appendix G

Assent Form (Audio Recording) - participant (12-16)

I _____ give my permission for the interview that I will have with Natasha Maswikiti to be audio recorded. I understand that:

- The tape and transcript (these are written documents which contain what has been said in the interview) will not be heard or seen by any people other than the researcher and research supervisor, who will keep what I said private.
- The recordings will be heard by the researcher and the research supervisor only.
- No personal information, such as names (yours, your family etc.) or places (where you live, where you are from etc.) will be used in the transcripts or the report.
- After the report is finished my interview recording and transcript will be kept in a safe place that only the researcher will have access to.

Signed _____

Date _____

Appendix H

Interview Schedule

(Preamble: I would like to discuss with you your experience of taking antiretroviral (ARV) medication as well as your thoughts and feelings around taking ARVs. If you do not understand any of the questions you may ask for them to be explained differently and if there are any questions you do not want to answer, that is also OK, we will carry on to talk about something else. You can take your time in answering the questions and please try to answer in as much detail as possible because I would like to learn from you so that we can have a better understanding of adolescents experience with ARVs).

1. When did you first learn about your HIV-positive status? How was this time for you?

2. Please tell me about when you first started taking ARV?/ Please tell me about when you were first told about taking ARTs
   a. What do you understand of ART and its purpose?
   b. How do you feel about being on ART?
   c. How often do you take your medicine

3. Who knows about your status?
   a. How is it for you that this/these person/people know your status?
   b. Who gives you your medication?
   c. How do you feel about this person?
   d. Does it make it easier/harder for you that this person knows your status and helps you with your medication?

4. Can you please tell me how you feel about having to take medication every day?
   a. What do you find easy about taking ARVs?
   b. What do you find difficult about taking ARVs?
   c. Do you ever forget take your medication as you should?
   d. What helps you remember to take your medicine at the right time every day?
   e. How do you manage to take your pills when you are away from home?

5. What does taking the medicine mean for you?

6. Do you ever think about or dream about stopping taking your medication?

7. Do you know of anyone that does not take their medication as they should?
   If yes, please elaborate as to what happens with this person.

8. Where do you collect your medicines?
    a. What is it like there? How do you feel going/being there?
    b. What is your relationship with your doctor/nurse like?

9. What would it mean for your life if you didn't have to take medication? What would be different for you?

10. What is it like being a teenager who has to take pills every day?

11. Is there anything else you think may be important for me to know that we haven't talked about?