

Factors influencing antiretroviral compliance in a small group of children between eight and twelve years of age

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Declaration

I hereby declare that the work presented in this thesis is original and my own unless otherwise stated.

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As the candidate's supervisor I have/have not approved this thesis/dissertation for submission.

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Abstract

The HIV/AIDS pandemic has implications at every level of social functioning. It affects individuals, families, communities and organisations. The burden of caring for those exposed, affected and infected is vast, but one of the most significant developments which have the potential to reduce disease burden is antiretroviral therapy. Antiretroviral therapy (ART) is complex and difficult to administer, and requires a learning process which is mediated through a number of means. Vygotskian theory was utilised to better understand the process of adherence through mediated learning, and as a framework for explaining compliance. In this study, mediated learning occurs both in the context of the clinic staff and the clinic attendees, and the caregivers and the child. Therefore Vygotsky's theory offers useful insight into this process.

This qualitative study aimed to research the factors which contribute to ART adherence in a small sample of HIV positive children who are attending a local clinic. Eight child-caregiver dyads were interviewed, and drawings utilised to better understand child and caregiver factors which contribute to compliance. There were a number of psychosocial factors identified which contribute to compliance, or lack thereof, including social support, stigma, medication fatigue, disclosure, access difficulties, psychoeducation, and motivation. A number of qualitative differences were also identified between children who knew their HIV status and those who did not. These differences emerged primarily through the analysis of the child participants' drawings and there appeared to be a number of inter- and intrapersonal benefits to disclosure. The factors identified in this study, if better understood, can inform interventions to improve compliance on ART.

Abbreviations and Acronyms

3TC	Lamivudine
ABC	Abacavir
AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
AZT	Zidovudine
ddI	Didanosine
d4T	Stavudine
DNA	Deoxyribonucleic Acid
EFV	Efavirenz
FDC	Fixed Drug Combination
FTC	Emtracitabine
HI	Human Immunodeficiency
HIV	Human Immunodeficiency Virus
HIV+	HIV positive
LPV/r	Lopinavir/Ritonavir
MDOT	Modified Directly Observed Treatment
MDR	Multi-drug resistant
MTCT	Mother-to-Child Transmission
NVP	Nevirapine
PCG	Primary caregiver
PMTCT	Prevention of Mother-to-Child Transmission
RNA	Ribonucleic Acid
TDF	Tenofovir
VL	Viral Load
WHO	World Health Organization
XDR	Extremely drug resistant

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Chapter 1: Introduction

The HIV/AIDS (Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome) pandemic has implications at every level of social functioning. It affects individuals, families, communities, businesses, and countries. The burden of the disease is felt not only by those infected with the disease and those who are directly affected by it, but also by society as a whole. The burden of death and disease are such, that wherever possible, attempts should be made to relieve this burden, and antiretroviral therapy (ART) is one of the means by which this is possible (Giacomet et al., 2003; Hammami et al., 2004). It is therefore important that the efforts in the field of HIV/AIDS include research into compliance and the factors which impact compliance on ART (Marhefka et al., 2008).

Antiretroviral (ARV) treatment reduces disease burden in a number of ways. An example of this is through improving the immune function, which reduces the rate of opportunistic infections and therefore the medical costs incurred by these infections, thereby improving the quality of life of sufferers (Mannheimer et al., 2005, McInerney et al. 2008). Correct use of ART also has the potential to improve general health status, and, therefore economic productivity, whilst maintaining family and community structures through decreased incidence of disease and death. Lastly, through improving the general health status of HIV positive (HIV+) individuals and therefore the disease burden (Davies, Egger, Keiser & Boule, 2009), ART can reduce the demand on already overtaxed public health services.

It is important to note, however, that the success of ART and the optimization of its benefits are contingent on their correct use (Cunningham, Naar-King, Ellis, Pejuan & Secord, 2006; Glass et al., 2010; Lyon et al., 2003; Mannheimer et al., 2005). Many factors have been explored in relation to this issue: however, there has been limited ART adherence research in sub-Saharan child populations, who are severely affected by HIV/AIDS (Davies, Boule, Fakir, Nuttall, & Eley, 2008). There is also limited research available which explores the issue of compliance in children, from the perspectives of both the child and the caregiver involved in the process

(Muller, Bode, Myer, Roux & von Steinbüchel, 2008). This research project attempted to address this deficit on a small scale.

This research aimed to explore and deepen understanding of the factors which influence compliance in taking ARV's, in children between the ages of eight and twelve years. It is recognised that these children are often reliant on adult assistance to take their medication (Cunningham et al., 2005), and therefore, the research explored issues around compliance from the perspective of the infected child and the caregiver responsible for the child's treatment. It is hoped that the findings will add to the existing body of literature around issues of ARV compliance and will offer further assistance in the goal of understanding why ARV compliance is a problem and how (if possible) it can be addressed, to the benefit of individuals, families and communities.

In order to explore the factors which impact ARV compliance in HIV+ children in the age group of eight to twelve years, personal, family and cognitive factors were the focus of this study. Other emerging factors were also investigated. The interviews explored issues such as: the practical aspects of medication and clinic attendance, medication-related knowledge, strategies for remembering medication, medication-related experiences, degree of compliance, understanding of medication action and purpose, challenges and coping strategies associated with medication use, social support, medication fatigue, and stress from responsibility. The study offered not only a deeper understanding of compliance and what factors influence compliance, but also provided insight into the early stages of medication-taking and what coping strategies and challenges were experienced during this stage. It considered the zone of proximal development in the Vygotskian theory of cognitive mediation as a theoretical model to understand adherence to ARVs in young children.

In order to better explain and understand the process of compliance, Vygotskian theory was utilised. Vygotsky's theory of mediated learning provides a model which offers insight into the social nature of learning. The training of caregivers and HIV+ children for correct ART compliance is a good example of learning on the interpersonal plane, therefore a Vygotskian frame will be described at a later stage.

Piaget's theory of cognitive development also offers useful insights into compliance and the learning process required for ART to be correctly adhered to. Piaget's theory grants understanding of the cognitive stages of the study participants, and the way in which these impact on their ART adherence. Bibace and Walsh (1980) provide an application of Piagetian theory to children's perceptions of illness, which will also be described.

The following chapter will provide a review of the current literature surrounding the issue of HIV/AIDS in order to position this study. Following this will be a brief description of Vygotsky's socio-cultural theory, with a specific focus on mediated learning, and its use in understanding the process of adherence. Piagetian theory will also be used to provide a theoretical frame for understanding the developmental stage of the sample. According to Piaget, the child participants fall into the concrete operational stage, which spans from seven to eleven years of age. The methods in terms of design, sampling and ethics will then be described.

The results of this study will then be presented and discussed in terms of the literature. They will also be explained in relation to Vygotsky's theory of cultural mediation, in which the role of caregivers is seen as important in scaffolding the process of treatment adherence. It will be shown that learning, in this instance, first takes place at the interpersonal level before it occurs at the intrapersonal level. In addition, the characteristic features of Bibace and Walsh's model of Piagetian application to children's understanding of health and illness is demonstrated in the concrete nature of their thought processes. Before concluding, the limitations of this study will be delineated and recommendations made, based on the study findings.

Chapter 2: Literature Review

Literature in the field of HIV/AIDS is readily available and covers a variety of issues and content. The literature also emerges from a variety of contexts with diverse challenges. In the following review, an attempt has been made to survey the factors which have a bearing on this study. However, due to the breadth of the content available, studies reviewed have been limited primarily, where possible, to those in African contexts and/or on child populations.

A brief explanation of HIV/AIDS will set the platform for the review, and will be followed by a summary of the important aspects of disease progression in the country to this point. Attention will then be drawn to the socio-political nature of treatment provision in South Africa, and the current ART guidelines will be presented. The review will then become more specific in exploring issues directly related to compliance. The issues covered will include the importance of research, the importance of compliance, a brief presentation of some suggested models for compliance, a discussion of some of the determinants of compliance identified in the literature, available measures of compliance, and the relative roles that caregivers and children play in compliance. The review will end with a discussion of methods for improving compliance which have been identified, both at micro-systemic and macro-systemic levels. In chapter three, Vygotsky's theory will be presented as the framework for understanding the process of adherence.

2.1 Description of HIV/AIDS

In order to situate this research study, it is necessary that a brief explanation of HIV/AIDS be given. It is also important that there is an understanding of the pathogenesis of the disease in order that the action and importance of ARVs be fully understood. As the pathophysiology of the disease is complex, the explanation will remain brief and somewhat superficial.

HIV is transmitted via direct contact with the body fluids of an infected individual. These body fluids include blood, cervical fluids and semen (Kumar & Clark, 2002). The virus, once in the blood stream, attaches to the receptor sites on the individual's CD4 cells, which are a component of the naturally occurring immune system. This cell is a lymphocyte (also called a helper-T cell), named for a certain receptor which occurs on its membrane, called a CD4 receptor. It is an important part of the body's cell-mediated immunity and its function in the body is to help mount a defense on invading organisms/infections. The HI (Human-Immune) virus enters healthy CD4 cells through the receptor and once inside the cell it undergoes a series of changes which ultimately lead to its integration into the host cell's DNA (deoxyribonucleic acid).

On its initial entry into the host cell, the virus alters its transfiguration through the action of the enzyme reverse transcriptase. It is then acted upon by the cell's own polymerase and transformed into DNA. Once it is transformed into DNA, another enzyme – this one a product of the virus – called viral integrase, enables the insertion of the new strands of viral DNA into the host cells' DNA (Longmore, Wilkinson, Turmezei & Cheung, 2007). This permanently alters the structure and function of the host cell, and instead of performing its protective function in the body, the cell becomes the site for multiplication of the virus. The virus is then released into the individual's bloodstream to infect other CD4 cells. The impact of HIV on the CD4 cells is thus two-fold: it prevents the CD4 cells from performing their correct function, and then kills off the CD4 cell by depleting it. The result of this depletion is the inadequate functioning of the immune system and therefore increased vulnerability to a variety of infections.

Once an individual is infected, the infection progresses through a series of stages (Jaspan, Nutall & Eley, 2005). These stages vary in the quantity of the virus in the body and the extent of the symptoms present. The initial incubation phase is asymptomatic and the virus is usually undetectable in the blood. This is followed by the seroconversion or primary illness phase during which there may be non-specific illness (Kumar & Clark, 2002). This stage is classified by the World Health Organisation (WHO) as primary infection. It is during this phase that the virus may become detectable in the blood. The individual will then enter a phase of varying length, called clinical latency, or Clinical Stage 1 (WHO, 2005) during which they remain

asymptomatic. This stage may last from several months to several years. There are a variety of factors which will have an impact on the duration of this phase, including socioeconomic status, gender, continued exposure, and pre-morbid health status (Jaspan et al., 2005).

As the body gradually succumbs to the infection, the infected individual will enter into the symptomatic infection phase. During this phase the viral load (i.e. the amount of the virus present in the individual's bloodstream) will increase and the CD4 count will decrease. The individual will develop a variety of signs and symptoms during this phase. Most of these symptoms will become clinically problematic and significant. According to the WHO Staging System (2005), this period coincides with Clinical Stages 2 and 3, where there will be varying infections of varying severity, worsening over time and accompanied by weight loss. Again, there will be a number of factors which will contribute to the duration of this phase.

In WHO Clinical Stage 4 (2005), the individual will develop a number of AIDS-defining conditions. The presence of one or more of these AIDS-defining conditions changes the client's status to AIDS, or what is colloquially termed "full-blown Aids". An alternate criterion for the diagnosis of AIDS is a CD4 count of less than $200/\text{mm}^3$ (Sande, Eliopoulos, Moellering & Gilbert, 2006). At this stage, the disease progression will be swift unless there is suitable intervention in the form of ART.

2.2 HIV/AIDS in South Africa

South Africa is severely affected by the HIV/AIDS pandemic, much like the rest of sub-Saharan Africa (Squire, 2007). Incidence and prevalence rates continue to increase in spite of the prevention campaigns which have been in place since 1994. The ineffectiveness of prevention programmes in stemming the spread of HIV/AIDS, draws attention to the notion that HIV/AIDS is more than a biological illness, it is a political, social and economic issue (Ndinga-Muvumba & Pharoah, 2008). South Africa is a country with vast political, social and economic divides and difficulties, and these have served to exacerbate the HIV/AIDS crisis in

the country. In order to better understand the current HIV/AIDS situation in South Africa, it will be discussed in terms of the history of the pandemic in this country and its progression.

It is currently estimated that 10.5% of the population of South Africa is HIV positive (STATSSA, 2010). This percentage translates into an estimated 5.24 million people living with HIV/AIDS, a figure which has increased since the early identification of the disease in the country. The voluntary testing of pregnant women in South Africa began in 1990 (STATSSA, 2010) and still remains the most reliable source for tracking the progression of the disease. The earliest cases of the disease were identified in the 1980s. The first democratic elections in South Africa saw former President Nelson Mandela taking leadership of a nation in which HIV/AIDS was already an important feature on the international agenda (Avert, 2010).

Due to the numerous developmental issues facing post-Apartheid South Africa, the national response was relatively ineffectual. South Africa then entered a term of HIV/AIDS denialism under former president Thabo Mbeki (Cullinan & Thom, 2009) during which time the provision of treatment was stalled. In spite of the delayed roll-out of ART, however, former President Mbeki's regime did draw attention to the link between HIV/AIDS disease progression and poverty (Coriat, 2008). This link is of significance particularly in an African context, where poverty is a major determinant of outcome in HIV/AIDS (Squire, 2007). However, this contribution does not negate the damage done by leadership to the early campaigns. Beginning during former President Mbeki's term as the deputy president, there were conflicting messages from the government regarding HIV/AIDS. These messages continued into the new millennium, punctuated by both the President and his Health Ministers. Doubts were cast on many aspects of the disease including its transmission, prognosis and treatment (Geffen, 2006).

Although the mixed messages at government level have to some degree persisted, the road ahead has held more promise as testing and treatment campaigns have gained momentum. The current strategic plans created by the government to carry on until 2012, place an emphasis on all spheres of the fight against HIV/AIDS (Department of Health, 2006). The strategic plans also include comprehensive prevention and treatment measures for all related conditions which

exacerbate HIV/AIDS, and occur as a result of it (Department of Health, 2006; Department of Health, 2010).

2.3 The socio-political nature of ART in South Africa

The management of HIV/AIDS and the use of ARVs in South Africa has been a highly charged and strongly contested one, with the issue becoming a political one at many levels. A discussion of HIV/AIDS and ARVs, therefore, requires that the very political nature of ART provision in South Africa be acknowledged. The provision of ART in South Africa was a process which took on political undertones early on during the HIV/AIDS epidemic in South Africa. The most widely publicized instance of denial of HIV/AIDS at a political level, and thus the thwarting of ARV provision in the country, occurred during former President Thabo Mbeki's term, when he and then Minister of Health Nkosazana Dlamini-Zuma, followed by the late Minister of Health Manto Tshabalala-Msimang, denied the link between HIV and AIDS. They encouraged the use of a number of alternate remedies, few of which had scientific backing (Cullinan and Thom, 2009). Many believe that the ground lost in the fight against HIV/AIDS during that period in South African history, cost countless lives, and has had an extremely negative effect on the progress of the disease in the country (Geffen, 2006; Heywood, 2004). The significant developments in the provision of ART in South Africa will be described below.

The first significant hurdle in the HIV/AIDS treatment campaign in South Africa was the introduction of Virodene (Cullinan & Thom, 2009). Virodene was tested without permission and, although the initial report implied that the remedy was effective, it was never recognised by the Medicines Control Council. The drug and its makers eventually left the limelight amid some scandal (Cullinan & Thom, 2009). During the Virodene campaign, the provision of AZT (Zidovudine) was stopped despite the international acceptance of the drug and its proven efficacy. AZT received bad publicity in the country and, once again, the provision of treatment to those infected was prevented. This was thus the second significant hurdle in the treatment campaign. In 2002, however, the government displayed an abrupt change of policy and

Nevirapine (NVP) was made available to HIV+ pregnant women and rape survivors (Natrass, 2006). The national ARV roll-out then followed in late 2003 (Squire, 2007).

An important role-player in the fight for ART provision in South Africa was the Treatment Action Campaign (TAC). The TAC was established in 1998 with the aim to ensure the provision of adequate health care for those infected with HIV/AIDS, in the form of both treatment and prevention programs (TAC, undated). Throughout the HIV/AIDS crisis, the TAC has opposed AIDS denialism, fighting for equal rights for HIV/AIDS infected individuals through protests and media releases which challenged the government's perceived inefficacy. In two papers released by the TAC, one by Mark Heywood (2004) and the other by Nathan Geffen (2006), attention was drawn to the government policy at the time, as well as the cost of denialism up to that point. Through papers such as these, and continuous protest against government policy, the TAC has played an important role in fighting for access to treatment and care for HIV/AIDS infected individuals in South Africa.

Although the country's ARV roll-out has since increased, the loss of life during the seemingly unnecessary four year wait has been the subject of much discussion and criticism of the Mbeki administration. Currently however, the estimated number of people on ART is 920 000, a dramatic increase from the numbers in 2005 which estimated that a mere 133 000 people were receiving treatment (STATSSA, 2010). It can thus be said that South Africa is certainly on the road to improvement, with access to ARVs advancing steadily in the country. This also draws attention to the fact that when the political leaders in the country consistently support such programmes, a great deal of ground can be made up.

An example of such a case is Uganda. Although also a country with a complex political history which resulted in a variety of challenges, the Ugandan government met the HIV/AIDS pandemic with a number of strategies. These were implemented consistently and radically, resulting in a currently negative HIV infection rate. At every level of government, there was firm commitment to the process of stemming the tide of infection. The president himself was involved, as were NGOs, churches, community leaders, schools and the healthcare system (Health a Key to Prosperity, undated). The Ugandan success story is a sign of hope for Africa,

demonstrating that when there is commitment and collaboration, the HIV/AIDS pandemic can be managed.

2.4 The South African ART guidelines

The National Strategic Plan 2007-2011, identified four priority areas for intervention, one being the scaling up of treatment plans in order to reduce morbidity and mortality of HIV/AIDS infected individuals (Department of Health, 2006). The broad aims of the plan included: the reduction of new infections; and the reduction of the impact of HIV/AIDS on families, individuals, communities and society through the use of treatment (Department of Health, 2006). There are a number of ART regimens which are clearly laid out in the government protocol. The criteria for assessment and various forms of treatment, and the management protocols are each clearly stipulated according to the policy guidelines. There are child-specific protocols, protocols for Prevention of Mother-to-Child Transmission (PMTCT) and pregnant women, and protocols for adults. To provide understanding about the context of the study and the lived experience of the participants, the South African guidelines for ART will be explained briefly.

The adult ART regimen consists of two lines of treatment, first- and second-line. The second-line of treatment is only commenced when there is proven failure of a first-line regimen. In order to qualify for the first line of treatment, the individual's CD4 count should be below $200/\text{mm}^3$ or they should be in Clinical Stage 4 (Department of Health, 2010). Pregnant women, and those with Tuberculosis (TB), qualify for treatment from a CD4 count of less than $350/\text{mm}^3$ and should be fast-tracked. Any individual with MDR (multi-drug resistant) or XDR (extremely drug resistant) TB should also commence treatment regardless of the CD4 count (Department of Health, 2010). The first-line treatment for adults includes: TDF (Tenofovir), 3TC/FTC (Lamivudine/Emtracitabine) and NVP/EFV (Nevirapine/Efavirenz); or d4T (Stavudine), 3TC and NVP/EFV; or AZT (Zidovudine), 3TC and NVP/EFV (Department of Health, 2010). These regimens and the second-line of treatment will not be explored in detail, as they are not applicable to the sample population.

The primary form of HIV transmission to children is from mother to child, also known as vertical transmission (Department of Health, 2010). Therefore, an important form of prevention for children is PMTCT. The government has initiated in-depth PMTCT programmes which were initiated in antenatal clinics throughout the country. The PMTCT programmes have components which are initiated at various points during the pregnancy and the birth of the infant. These programmes have been seen to have a good effect on the reduction of vertical transmission in both resource-rich and resource-poor contexts (Department of Health, 2010). The programme commences with the voluntary testing of a pregnant woman, using the HIV rapid test. The testing is accompanied by pre- and post-test counselling. If the pregnant woman tests positive, her CD4 count will be monitored. Once it reaches $350/\text{mm}^3$ or below, she will be commenced on ARVs, which she will then take for the rest of her life. If, however, the woman meets the criteria for Clinical Stage 3 or 4, regardless of her CD4 count, she will be commenced on treatment. She will also receive a single dose of NVP during labour and a single dose of TDF and FTC post-delivery (Department of Health, 2010).

Once it is established that an infant has been exposed to the risk of HIV infection, there is a protocol for follow-up and management. This protocol includes guidelines for the commencement of testing and the frequency of re-testing, initiation of ART, and supportive management of opportunistic infections. During the follow-up, once the child meets the criteria, ART first-line treatment will be started, with second-line treatment only being utilised when there is proven treatment failure of the first-line regimen. The criteria for commencement of ART in children are as follows: all children below the age of one year who test positive; from one to five years of age: Clinical Stage 3 or 4, CD4 count less than $750/\text{mm}^3$ or less than 25%; children five years or older: Clinical Stage 3 or 4, or CD4 count of less than $350/\text{mm}^3$ (Department of Health, 2010).

The first-line of treatment includes ABC (Abacavir), 3TC, and LPV/r (Lopinavir/Ritonavir) in children less than three years of age; and ABC, AZT and EFV in children over three years of age (Department of Health, 2010). The original regimen included d4T instead of ABC and this can be continued unless there are problematic side-effects noted (Department of Health, 2010). Depending on the child's age and the availability of various dosage forms, younger children will be put on suspensions or syrups, whilst the older children will be given tablets. The

children in this study were all on the tablet forms of the medications (see Appendix A for pictures of these medications). The medications will, however, look slightly different dependant on which pharmaceutical company makes them. Depending on the child's weight and the strength of the tablet, a child may be taking anything from four to six tablets in the morning, and three to five tablets in the evening (Department of Health, 2010). The second-line of treatment will not be described in detail, as it is not applicable to the sample group.

There are a number of important considerations for administration, specific to ART, which must be taken into account in order to have optimum efficacy of the drugs. The first is complete adherence at all times, for the rest of the person's life. Once commenced, ART should not be stopped, nor any doses be missed (Gibbon, 2003). The reason for this is the tendency of the virus to mutate in order to survive. If inadequately suppressed through ART, the virus may become resistant to these treatments (Department of Health, 2010), which ultimately causes a decline in prognosis as the virus eventually becomes untreatable.

The second important consideration is that the doses must be given at strict intervals to ensure adequate viral suppression (Gibbon, 2003). Certain of the drugs are given at 12 hourly intervals (d4T, AZT, 3TC and ABC), and others are given only daily (EFV). If the intervals are not strictly adhered to, there may be treatment failure and viral mutation, increasing the risk of resistance formation. There are also a number of dietary requirements which have an impact on the efficacy of treatment. Medications should be given with food in order to reduce the incidence of nausea and vomiting, although in addition to this, regular meals should be prioritised whenever possible because good nutrition is also essential for the strengthening of the immune system, and thus should be encouraged in all HIV+ children (Department of Health, 2010).

2.5 Importance of research

According to current literature, there is a definite dearth of studies on African children, in spite of the fact that the majority of HIV infected children live in sub-Saharan Africa (Arrive et al.,

2005; Davies et al, 2008; Muller et al., 2008). This is disturbing in that for ART to be effective there must be near-to-perfect compliance. Therefore, the factors which have an impact on ARV adherence should be a research focus which is prioritised in order to increase the survival rates of those infected, and decrease risk of resistance and transmission (Marhefka et al, 2008). Marhefka and colleagues (2008) raise a further important point, noting that beyond merely researching child compliance, there should be an attempt to understand the experiences of families in relation to adherence on ART regimens. In this way, all the factors which contribute to success of treatment can be identified and utilised to inform adherence-promoting interventions.

Of the research which is available in respect of ARV adherence in children, there is an emphasis on barriers to adherence, with a shortage of information regarding specific regimen-related strategies. Whilst the available information on barriers to adherence is very useful, some of these factors, such as poverty, are not easy to address. It is, therefore, important that there be information available not only on factors which may be removed, but also those which may either be introduced at a microsystemic level, or improved upon. This includes strategies for remembering medication, accessing social support, sharing responsibility, and so forth. Therefore, this study has focused not only on barriers, but rather on a broad set of factors which influence adherence, be they positive or negative.

2.6 Importance of compliance

A number of studies note the importance of compliance on ART (Albano et al., 2007; Hammami et al., 2004; Marhefka et al., 2006; Muller et al.; 2008; Steele & Grauer, 2003) and it is believed that even in resource-poor contexts, correct administration can dramatically improve outcomes for HIV infected children (Davies et al., 2008). It has been generally accepted that ART has the potential to greatly increase the quality of life of those infected. However, if there is incomplete adherence to the regimen, the result is decreased viral suppression, increased viral load and the development of mutated or resistant forms of the disease (McInerney et al., 2008; Muller et al., 2008; Steele & Grauer, 2003). This also then has

an impact on the frequency of hospitalisation and antibiotic usage by those infected (Glass et al., 2010).

In a recent meta-analysis by Mills and colleagues (2006), it was found, contrary to expectations, that in fact there are favourable levels of adherence in sub-Saharan Africa. The measures were based primarily on self-report and were predominantly studies using adult participants. However, it has been a very positive finding with regards to ARV usage in resource-poor contexts such as sub-Saharan Africa. Slightly more recent studies conducted in KwaZulu-Natal by Reddi and colleagues (2007), in the Western Cape by Muller and colleagues (2008), and in Western Kenya by Vreeman and colleagues (2008) also found that in spite of the limited resources, adherence could be favourable. It is, however, duly noted by Mills and colleagues (2006) that there are a number of factors which may affect adherence over time, and thus there should be ongoing emphasis on monitoring adherence over time. This summation by Mills (2006) was confirmed by Dalal and colleagues in their 2008 study in Johannesburg. They found that one in six adults on ART were lost to follow-up over a fifteen month period. Monitoring adherence over time and retaining clients in treatment programmes should, therefore, remain a priority in spite of currently reported high adherence.

2.7 Models of compliance

At this stage in the HIV/AIDS pandemic, there are few models of compliance which have been developed and proven to be good predictors, although some work into this area is beginning to be done. For example, Diiorio and colleagues (2009) tested a psychosocial model for adherence and found that self-efficacy and depression had direct correlations with medication compliance. In another study, the health belief model was tested on caregivers in order to assess the relationship between their perceived vulnerabilities and barriers in relation to adherence (Steele et al, 2001). The study, however, failed to show any relationship between these variables and adherence. McInerney and colleagues (2008) also tested a model, but its focus was on determining the predictors of physical functioning on ART. Even though a number of variables were tested, they only served to account for 29% of variance. Thus, it is still an area in need of further development and research. Due to the scarcity of these models and the shortage of

studies on South African child populations, the approach taken in this study was exploratory rather than interpretive.

2.8 Determinants of compliance

As previously mentioned, the majority of studies in the area of ART have focused on factors which affect compliance. These factors fall into a number of broad categories. For the purpose of this discussion, these factors will be discussed under four headings: psychological factors, social factors, economic factors and regimen-related factors.

2.8.1 Psychological factors

There are a number of psychological factors which have been found to be associated with compliance on ART (Giacomet et al., 2003). Different studies have identified these factors and there is a high degree of consensus as to what they are. Some of these factors will be briefly described, and then referred to in more detail in the discussion concerning child and caregiver factors contributing to compliance. Marhefka and colleagues have identified stress, quality of life and communication; Byakika-Tusiime and colleagues conducted a study which found that depression had an impact on adherence. This finding regarding depression was supported by Diiorio and colleagues (2009), and by Lyon and colleagues (2003). The findings regarding stress and/or stressful life events have also been confirmed in several studies (Glass et al., 2010; Malee et al., 2009, Merenstein et al., 2009). Motivation, problem-solving ability, and self-efficacy have also been associated with better adherence (Hammami et al., 2004; Lyon et al., 2003)

A psychological factor which has been explored, but found to have no impact, is the cognitive functioning of the individual (Malee et al., 2009). Malee and colleagues (2009) hypothesised that the individual's level of intelligence would have an impact on their adherence; this however, did not serve as a good predictor of adherence. Another unexpected finding was that

a child knowing his/her HIV/AIDS status did not in fact improve adherence (Giacomet et al, 2003; Marhefka et al, 2006; Merzel, VanDevanter & Irvine, 2008).

2.8.2 Social factors

Two important social factors, which have been shown to have an impact on adherence, are stigma and social support. Stigma has been found in a number of studies to have a negative impact on adherence (Byakika-Tusiime et al., 2009; Dlamini et al., 2009; Ncama et al., 2008; Petersen et al., 2010; Steele & Grauer, 2003). Dlamini and colleagues (2009) suggest that the reason for this is that to consistently and correctly take medication, HIV infected individuals may face the exposure of their illness to their friends and family. This exposure may lead to negative interpersonal consequences for these individuals.

The second social factor identified can be considered a protective factor. In most current research studies, there is recognition of the role of social support in improving adherence. In adults this support may be in the form of emotional support, and reminders about medication. In children, however, this may take on a more practical form of assistance with giving medication, or dividing responsibility to reduce regimen fatigue (Lyon et al., 2003; Merzel et al., 2008; Ncama et al., 2008; Parantham, Kumarasamy, Bella & Webster, 2009; Petersen et al., 2010). Regimen fatigue can be understood as tiredness: experienced by those responsible for medication administration; and by the client, due to the demanding nature of the medication routine and the complexities of correct adherence (Merzel et al., 2008). For these reasons, where possible, appropriate forms of support should be accessed by individuals on ART, and/or the caregivers of such individuals. They should be encouraged and assisted in this where possible (Department of Health, 2010).

2.8.3 Economic factors

The predominant economic factor identified in literature, is poverty (Petersen et al., 2010; Rosen, Ketlhapile, Sanne & De Silva, 2007). This naturally has a number of ramifications on

the various requirements for complete compliance. The two most important issues identified in the literature in this regard, are the lack of transportation money and cost of the treatment (Byakika-Tusiime et al., 2009; Parantham et al., 2009; Petersen et al., 2010). Although, in the context of this particular study, treatment is free, the issue of transport remains a significant threat to adherence and clinic attendance in all resource-poor contexts. In the initial phases of treatment, according to the national guidelines (Department of Health, 2010), multiple visits are required over a short period of time. The difficulties which may be experienced by clients and caregivers in this regard, may result in early defaulting, and should therefore be viewed in a serious light. Further costs which may be incurred, although not noted in the literature, include time off work, and refreshment during the day of the clinic visit.

2.8.4 Regimen-related factors

There are five interrelated, but distinct factors related to the ART regimen which have been identified in research studies and reviews. These five factors include: poor palatability, poor packaging and formulation, side-effects and health concerns about ART, complexity of the regime and regimen fatigue (Byakika-Tusiime et al., 2009; Davies et al., 2008; Lyon et al., 2003; Merzel et al., 2008; Muller et al., 2008; Parantham et al., 2009; Reddington et al., 2009; Schonnesson et al., 2006; Steele & Grauer, 2003; Voss et al., 2006). Although these factors are not all easy to address, attempts are being made to reduce some of the negative aspects of treatment. Examples of such attempts include the introduction of medications with an improved side-effect profile (e.g. ABC in place of d4T), and the development of combined dose medications (Department of Health, 2006; Department of Health, 2010). Whilst this is an important area where continued development is required, at present there are some regimen-related factors which remain a threat to adherence.

2.9 Measures of compliance

There are a number of studies to date which have focused on the measurement and evaluation of adherence. Although many of these studies have focused on adult populations in different contexts, there is some measure of agreement as to how compliance can be assessed and/or

quantified. Due to the ethical restrictions of this study, only self-report of compliance was utilised as a measure. There were, however, some other measures which have been used in the studies reviewed, and these will be described briefly.

According to literature, for an individual to be considered compliant (or adherent) there should be a minimum number of doses missed, but there are varying cut-off points which are considered necessary. Some of the literature presents this cut-off as 80% (Marhefka et al., 2006), while other sources place the cut-off much higher, at 90-95% (Albano et al., 2007; Hammami et al., 2004; Marhefka et al., 2008). These measures are based on the required number of doses believed necessary to maintain viral suppression. However, for the purposes of this study there was neither the need nor provision to evaluate adherence in this manner.

Other measures utilised commonly include: pharmacy refill rate (Marhefka et al., 2006) and medication return (Davies et al., 2008; Farley et al., 2008), viral suppression using baseline viral load (VL) and CD4 counts at 6 months (Marhefka et al., 2006), and self-report of doses missed in the past few days (Albano et al., 2007; Arrive et al., 2005; Farley et al., 2008; Schonnesson et al., 2006). These findings are often verified by using physician and/or nursing staff estimates, as caregiver report in certain contexts is believed to be unreliable (Muller et al., 2008). However, discrepancies seem to exist with professional estimate, with physician estimate generally being routinely lower than self-report (Albano et al., 2007).

2.10 Compliance in HIV positive children

In order to discuss compliance in children, it is important to note that child compliance is usually contingent on caregivers correctly and consistently administering their medication. Thus the role of the child themselves is not of solitary significance (Muller et al., 2008). This is not to say that the child's role is of no significance however. The child should in fact be included wherever possible (Cunningham et al., 2006). In order to better understand ARV compliance in children, the issue has been examined from the perspective of the parents and the child, both in the research and in the following discussion. Caregiver factors will be considered first, followed by child factors which have a role to play in adherence.

2.10.1 Caregiver factors

Literature has confirmed that there are a number of identified caregiver factors which are extremely important indicators of treatment compliance in children (Cunningham et al., 2005; Merenstein et al., 2009; Muller et al., 2009 & Vreeman et al, 2008). These factors include interpersonal factors, socio-demographic factors, psychological factors, and HIV status. In several studies, an important factor which contributed to better compliance was a non-related caregiver, who did not disclose the child's status to him/her (Giacomet et al., 2003; Marhefka et al., 2006). The issue of non-disclosure to the infected child will be discussed in more detail below. The correlation of non-related caregiver with improved compliance is believed to be connected to the training of foster parents in caring for a child with HIV/AIDS (Giacomet et al., 2003). This was, however, a finding in a non-African population and may not have relevance to the context of this study. In another study, it was found that caregiver's knowledge of their own sero-status, and higher income, were associated with adherence (Marhefka et al., 2006). It was also found that caregivers with a higher perception of barriers to adherence, who suffer from depression and who suffer from a variety of stressors (Diiorio et al., 2009; Lyon et al., 2003; Schonnesson et al., 2006), are less likely to have adherent children.

There have, however, been some factors on which no consensus has been reached in the literature. Some studies have identified that caregiver age, education, substance abuse history, HIV status, perceived helpfulness of support structures, reported stress and reported need for social support are not correlated with adherence (Marhefka et al., 2006). Although, in other studies, some of these predictors, such as certain socio-demographic factors (Schonnesson et al., 2006) were also found to be of little significance, the majority of studies recognise that life stress and social support are important predictors of adherence (Merzel et al., 2008; Ncama et al., 2008; Parantham et al., 2009; Petersen et al., 2010).

2.10.2 Child Factors

As has been discussed, the role of the caregiver in managing adherence for children on ART is extremely important. However, it is necessary that the child be a part of the process. This is not

to say that disclosure of the child's status should occur immediately, as literature to date has shown that non-disclosure of the child's status is associated with improved adherence (Giacomet et al, 2003; Marhefka et al, 2006; Merzel et al., 2008). It is possible that the reason for this is that once children are informed of their status, they may be expected to take responsibility for their medication prematurely (Marhefka et al., 2006). Rather, it may be necessary for caregivers to retain responsibility for certain regimen-related tasks, while delegating others to the child, in order to increase adherence (Marhefka et al., 2008).

Literature has also shown that decreased adherence may be related to age, denial, anger and dislike for the daily reminder of their status, as well as inconsistent adherence in certain settings due to fear of others finding out (Dlamini et al., 2009). Two further factors which may have an impact on compliance in children were identified by Schonnesson and colleagues (2006), namely that HIV concerns may function as motivators to adhere, and that pressure by close friends and family may be associated with poorer compliance.

A factor which may have a role to play in adherence, but which has not been researched much, is that of resilience. Resilience is defined by Theron and Theron (2010) as positive adaptation to adversity. It is a topic which has received much attention in the past few years, but as yet, it has not been investigated as a correlate or determinant of adherence to ART. It is potentially an area which should receive greater attention in the future and which may offer insight into compliance in African contexts.

2.11 Improving compliance

Due to the importance of compliance on ART, it is essential that, wherever possible, there are interventions which facilitate and improve adherence. These interventions may be at a micro- or macro-systemic level. Some of the strategies identified in literature, both individual and systemic, will be discussed briefly.

2.11.1 Individual compliance strategies

Certain studies have shown that memory strategies, regardless of how many are used, have not shown an increase in adherence in families who struggle to remember medication (Marhefka et al., 2008). However, Lyon and colleagues (2003) found that multi-alarm watches were useful as reminders of ART in a group of adolescents. They found that these watches served a dual purpose, reminding the client to take their medication, but also giving them a sense of value to the researchers, as well as a sense of being supported.

This sense of being supported and assisted to remember medication has been found in other studies to be a strategy to improve adherence (Cunningham et al., 2006; Lyon et al., 2003). In the case of caregivers, assistance in remembering medication has also been reported as a strategy for improved compliance. On the issue of support for remembering treatment, it is also important to note that there be supportive and age appropriate handing over of responsibility of treatment-taking in order to ensure compliance (Arrive et al., 2005). Programmes which encourage support for remembering medication are useful in this regard and will be discussed briefly below.

2.11.2 Improving compliance through systems and programs

In order to improve adherence it must be understood that compliance is a process, and should not be assessed on a single occasion. It should rather be monitored consistently over time through the use of multiple periodic assessments (Schonnesson et al., 2006). Multiple periodic assessments also allow for the identification of individual difference with regards to treatment barriers so that interventions to improve compliance can be tailored to each individuals needs (Lyon et al., 2003).

Literature has also shown that the quality of the relationships with the medical professionals and their active involvement in the treatment regime and monitoring of adherence (Lyon et al., 2003; Schonnesson et al., 2006) are important predictors of adherence. Caring and trusting

relationships with healthcare professionals and pressure from them to adhere to treatment have been found to be predictors of improved compliance.

Programmes which run parallel to, or in conjunction with the provision of treatment, offer support for remembering medication in the community and/or home environment. Two examples of such programmes are: modified direct observation of treatment (MDOT) programmes (Garvie et al., 2009); and MST or multi-systemic therapy (Cunningham et al., 2006). In both these instances, there is assistance in remembering medications, and correct dosage requirements by friends and family and/or professionals. The studies by Garvie and colleagues (2009) and Cunningham and colleagues (2006) both found that such methods would be desirable and feasible in resource-limited settings, and should thus be considered.

2.12 Summary of consistent findings regarding compliance

There are a number of factors which have been identified in the literature as having an influence on adherence. These factors can be broadly grouped into four categories: caregiver factors, child factors, medication factors and access difficulties.

A number of caregiver factors have been consistently identified in the literature as contributing to compliance. Social support has been found to increase adherence, whilst stigma decreases it. Life stress and depression have also been found to be linked to decreased adherence, and motivation, problem-solving and self-efficacy tends to improve adherence. Literature has also identified quality of life on medication as a factor with the potential to improve compliance. The child factors which were identified were also a combination of psychosocial factors and demographic factors. Factors which were consistently found to increase adherence were non-disclosure of the child's status to him/her. Factors which were associated with decreased compliance, on the other hand, were older age, denial, anger and stigma.

An important access difficulty identified as having a negative impact on adherence, was the cost of accessing medications (primarily transport). In line with this finding is that higher income is associated with improved compliance. The final category is the presence of a number of regimen-related factors, which included: palatability, formulation, side effects, complexity of the regimen and regimen fatigue.

Chapter 3: Theoretical approaches to understanding compliance

3.1 Vygotsky and compliance

Vygotskian theory offers useful insights into the process of learning. Although usually applied to the process of child development and learning, it also offers a framework for understanding the way in which ART administration and adherence can be learned. However, in order to understand this theory's possible contributions to ARV compliance, the theory and its associated concepts must be explained. Following this, the application of mediated learning to ART adherence will be briefly explored.

3.1.1 Overview of Vygotskian theory

According to Vygotsky, learning is social and occurs through interaction with our environment and the people around us (Vygotsky in Wertsch & Kanner, 1992). He understood development of higher mental processes (HMP) to occur first on the social (or interpersonal) plane, and then on the psychological (or intrapersonal) plane (Vygotsky, 1981 in Wertsch & Kanner, 1992). The relationship between these two planes can be understood in terms of mediation and internalisation. Mediation is a pivotal concept in Vygotskian theory and, according to Vygotsky, is the process of learning which occurs when skills are learnt through the instruction and assistance of a more knowledgeable other (Vygotsky, 1978). When effective mediation occurs, it enhances the learner's zone of proximal development (ZPD). The ZPD is a term used by Vygotsky to describe the difference between a learner's actual ability and their potential ability when assisted by a more knowledgeable other (Vygotsky, 1978).

Once experienced on the social plane, knowledge is then internalised. The processes of mediation and internalisation are achieved through the use of signs and tools (Hook, Watts & Cockcroft, 2002). Simplified, signs are those things which act on the psychological plane (i.e. internally oriented) and tools are those things with which individuals act on the world around

them (i.e. externally oriented) (Vygotsky, 1978). The use of signs and tools transform the nature of thought and the way in which individuals think. Each of these important concepts of Vygotsky's theory will be elaborated on below.

Vygotsky's theory emerged in response to the pervasive behaviourist ideology of the time, which viewed learning as universal in nature and occurring as a simple matter of stimulus and response. From the behaviourist perspective, learning occurs by imitation and is purely biological in nature. Vygotsky offered a theory which instead considered the individual's context, their cultural and social milieu, and the way in which learning occurs through interaction with other people, particularly those who are more knowledgeable than oneself (Hook et al., 2002). Vygotsky's theory also contrasted against the Piagetian view of learning as sequential, biological and therefore universal. Vygotsky viewed learning as embedded in context and individually specific in the way in which it occurs (Wertsch & Kanner, 1992).

Vygotsky was more interested in the process of learning than the product of learning. According to Vygotsky, the primary processes by which individuals learn, are the processes of mediation and internalisation. Mediation in essence can be understood as a form of apprenticeship. It involves learning from more knowledgeable others, through the social nature of activity, skills which are beyond current capabilities. Effective mediation is mediation which activates dormant capabilities, or which stimulates currently maturing capabilities (Wertsch and Kanner, 1992). Signs and tools are the means by which mediation occurs. These include language, counting, art, writing and so forth (Wertsch & Kanner, 1992). Language is the pervasive means of mediation, particularly in relation to the social learning (interpersonal dimension) which occurs between adults and children (Hook et al., 2002), and clinic attendees and clinic staff. Various other signs and tools are also used in the mediation of treatment compliance. These include clinic attendance and clinic staff, reminders on cell phones or alarms at medication times, or certain television programmes as reminders.

Before further explaining the role of signs and tools, the concept of internalisation must be described briefly. Internalisation is the process whereby external operations are reconstructed internally (Vygotsky, 1978). An example of this is the way in which a young child will

verbally instruct him/herself out loud, but gradually develop the ability to perform the same activity without self-regulating through speech. The process in fact begins before that, when the child's parent was giving the instruction verbally to the child, and it occurs in stages. Initially individuals are regulated by others (inter-psychological). They then develop the ability to self-regulate (intra-psychological), first through verbal expression and then silently (or internally). It is this process which is called internalisation (Vygotsky, 1978).

Signs are internally oriented and their goal is the mastering of oneself (Vygotsky, 1978). Signs qualitatively change intra-mental functioning, but do not cause change in the object of psychological operation (Vygotsky, 1978). A tool, on the other hand, is externally oriented and is used to master objects in the world. The use of tools qualitatively changes the objects upon which they act (Vygotsky, 1978). Tools and signs affect each other, just as man and nature affect each other (Vygotsky, 1978). According to Vygotsky (1978), man's alteration of nature alters his own nature, and therefore signs and tools should not be viewed as isolated from each other. In this study, examples of potential signs include reminders and verbal cues. Examples of tools include the tablet container, a glass of water and verbal instructions.

The final concept which requires explanation is that of the zone of proximal development (ZPD). According to Vygotsky, the ZPD is the "distance between a child's actual developmental level as determined by independent problem solving and the higher level of potential development as determined through problem solving under adult guidance or in collaboration with more capable peers" (Wertsch & Kanner, 1992, p. 332). The ZPD is created and expanded through learning, and in Vygotsky's view, is a preferred and more accurate measure of intellectual ability. The actual developmental level can be viewed as that which has already been achieved in the child's intellectual development, whereas the ZPD can be considered as the imminent developmental level, and therefore a more accurate measure of potential capability.

3.1.2 Application of Vygotsky's theory of mediated learning to ARV adherence

ART is notoriously complex to administer, being very specific in its requirements (Cunningham et al., 2005; Garvie et al., 2009, Msellati et al., 2008). The nature of the drugs and their action in the body are difficult to understand, and health professionals who administer and prescribe the drugs require specialised training (Department of Health, 2010). Therefore, in order for these drugs to be correctly administered and for efficacy to be maintained, individuals who take them, or administer them, also require specialised training. This training can be likened to a form of mediated learning.

In the clinic context, an example of mediated learning is the process whereby the clinic staff, who are the more knowledgeable regarding ART, facilitate the learning process of the clinic attendees who are less knowledgeable regarding ART. It can also be seen in the process of the caregiver mediating the learning of the child, of how to correctly take their medication. A third application would be in programmes such as MDOT programmes mentioned earlier, in which others who have been on treatment or who have a knowledge of the regimens, assist and facilitate correct administration of the drugs in the individual's home environment.

An important aspect of mediated learning alluded to above, is that learning cannot exceed developmental capability, but rather serves to activate dormant capabilities. Adult caregivers are able to acquire the complex skills required for compliance through mediation, and are therefore the focus of the initial training. As the ZPD of these caregivers is increased, they then become increasingly equipped to pass this knowledge on to the child through the same process. However, it cannot be assumed that a young child will be able to internalise the requirements of the ART regimen before they are developmentally able to do so. Therefore, in order for this process to be effective, the mediation must be developmentally appropriate. It is at this point that the Piagetian theory offers useful insight.

3.2. Piagetian contributions

Piaget's cognitive developmental theory is universal in its nature, assuming that all children, regardless of their context, move through a series of four stages of development (Hook et al., 2002). Each stage is characterised by certain ways of understanding and interacting with the world, as the child moves from the exploratory behaviours seen in infants and toddlers, to abstract and logical reasoning abilities evident in adolescence and adulthood (Hook et al., 2003). The four stages are as follows:

- Sensorimotor stage – birth to two years
- Preoperational stage – two to seven years
- Concrete operational stage – seven to eleven years
- Formal operational stage – eleven years and older

The child participants in this study were between eight and eleven years of age, therefore only this stage will be explained in more detail.

The concrete operational stage is characterised by the development of four important abilities, which mark the early transition into more logical and flexible forms of thought (Hook et al., 2002). These abilities include: hierarchical classification, seriation, conservation and spatial reasoning (Hook et al., 2002). While this improved ability to organize information offers the opportunity for children on ART to remember their medication and describe what it looks like, or know what tablets should be taken morning and evening, there is an important limitation in this stage which is significant in this regard. In this stage, children lack the capacity for abstract reasoning. This means that their understanding of both the disease process of HIV/AIDS and the action of the medication may be beyond their grasp. Therefore, the potential exists for decreased compliance. It is for this reason that children still require assistance from a more knowledgeable party in adhering to their medication.

Bibace and Walsh (1980) used Piaget's theory to provide an explanation of children's conceptions of illness, and the way in which they change as cognitive developmental changes occur. Bibace and Walsh (1980) identified specific stages of illness conception, with two primary strategies for understanding illness emerging in the concrete operational stage (i.e. the developmental stage of the study sample). These two strategies were contamination and internalisation (Bibace and Walsh, 1980). The characteristics of these two strategies were identified as the increased differentiation of self and other, the other being a source of illness outside of the body, but its harmful action being inside the body. The understanding of these stages by caregivers and medical professionals would offer extremely valuable insight into the way in which illness and treatment are explained – including HIV/AIDS and ART.

With the increasing burden of HIV/AIDS and the increased research focus in the area, Bibace and Walsh (1990) also offered an explanation, based on their previous work, of HIV/AIDS and children's conceptions of the illness. Their findings in this study were very similar to their findings in their previous study of children's conceptions of illness (1980). It again emerged that children's understanding of HIV/AIDS, the way in which it is contracted and how it affects the body, remained concrete. The findings of this study serve to reiterate the need for developmentally appropriate education of children infected with HIV/AIDS.

Chapter 4: Research methodology and methods

4.1 Research design

This research project took the form of a qualitative descriptive study. This design was selected as it allowed detailed, personal descriptions and accounts to emerge from the participants (Terre Blanche, Durrheim & Painter, 2006): in this case, the primary caregiver (PCG) and the child. The questions asked in the study focused on those issues that had already been identified as significant in ARV compliance and explored for a deeper and more holistic understanding of the variables that affect ARV compliance in a group of HIV positive children being treated with ARVs.

4.2 Sampling

Sampling of participants was purposive, to a total of eight child-caregiver dyads. Purposive sampling was selected due to the specific aim of the study – the exploration of experiences around ARV compliance and the factors which affect compliance in children between the ages of eight and twelve years. According to Terre Blanche et al. (2006), purposive sampling can be used when cases are selected, as they are good examples of the phenomena under study. The participants were initially to be selected by a medical doctor at the clinic, based on the following criteria:

- Child between the ages of eight and twelve years.
- Clinic appointment scheduled for the selected data collection week in order to minimize inconvenience to the clients (this criterion is used for the convenience of the researcher who has limited time to collect data).
- Caregiver attending the clinic should know the child well and be responsible for the child's well-being for at least five to six days per week. This was to ensure that the caregiver was familiar with the child and the medication requirements. Many children are taken to the clinic by relatives who may not be primarily responsible for the child's

medication. It was important to screen out such individuals as it was likely that they were not familiar with the topic under review (i.e. ARV compliance).

- These criteria may of course bias the sample, as those who attend the clinic are more likely to be adhering to the treatment. However, this study was exploratory in its nature and the findings can still be utilised.

On arrival at the clinic, it was discovered that the medical doctors had been unable to select the volunteers due to the unpredictable nature of appointment arrivals, and the pressure under which the clinic staff were working. In addition to this, for many of the clients at the clinic, remaining behind after their doctor's appointment was completed was very difficult due to transport needs and time pressure. Therefore, it was decided that volunteers would be selected based on the above criteria, but allowed to volunteer for the process and be interviewed while waiting to see the doctor. The volunteer process was initiated by first explaining the age criterion, and then asking for a show of hands of those willing to be interviewed. Once these caregivers volunteered, they were approached individually, given further details of the study, and given the opportunity to participate should they so wish. Approximately 50% of the clinic attendees within the stipulated age range volunteered in this manner. This method was successful and a group of eight child-caregiver dyads, who met the selection criteria, were sampled.

4.3 Instruments

4.3.1 Interviews

During the interviews (see Appendices B and C), basic information regarding caregiver knowledge of HIV/AIDS and treatment was ascertained, medication administration techniques and reminders explored, and degree of self-reported compliance recorded. An attempt was made to determine what problems contributed to lack of compliance, or which factors contributed to good compliance. Some of the challenges faced by the caregiver regarding their child's treatment were also explored. The interview questions were generated bearing in mind

the current literature, the research aim and the sensitive nature of the topic in question. They provided a guideline upon which the discussion could be built.

4.3.2 Drawings

Drawings were utilised in an attempt to create a sense of safety. Due to the less threatening nature of drawing and play, this enhanced the interaction and relationship between the child and the researcher (Watts & Garza, 2008). The drawings were of two forms: simple “gingerbread man” pictures, and various projective drawing-type tests, including asking participants to draw a picture of themselves and their caregiver coming to the clinic.

The gingerbread man pictures were intended to allow the child to colour in and draw, in order to provide an opportunity for the child participants to communicate their understandings of the disease process and the effect of medication in a non-verbal manner (see Appendices D and E for the manner in which these drawings were included). It was anticipated that the use of drawings would enable a deeper understanding of the child’s comprehension and experiences of their medication and their illness, than would have been possible through verbal communication (Landreth, 2002 in Watts & Garza, 2008).

Drawings were analyzed using Koppitz’s system for evaluating child drawings. Koppitz (1968) is a frequently used model for interpreting children’s drawings for the presence of emotional indicators (EI). Koppitz developed her list of emotional indicators on the basis of a sample of 1,856 American school children, between the ages of five and twelve years eleven months (Koppitz, 1968). Drawings were analysed using a simple checklist to assess for the presence of emotional indicators. The related hypothesis associated with each EI were then considered. For example (i) the presence of a small head is considered to occur more frequently in the drawings of children who have intense feelings of intellectual inadequacy; and (ii) the absence of hands is considered to occur more frequently in children who experience feelings of inadequacy or guilt.

The apparent lack of validity and reliability of projective assessment tools has always been strongly critiqued. The use of drawings as a projective technique for children has also been widely criticised, nevertheless, drawings remain one of the most frequently used clinical assessment procedures used with children (Thomas & Jolley, 1998). In addition, the lack of standardisation in the administration of the drawing tests has been cause for concern for many (Rae & Hyland, 2001).

The westernised nature of the interpretive guidelines for the analysis of the drawings must be mentioned at this point. Whilst projective tools may be thought of by some as universal in nature, it is important to note that the meaning of certain symbols may have cultural significance which is not accounted for, or which is inappropriate to the South African context (Richter, Griesel & Wortley, 1989). This may imply that projective drawings may be an inaccurate measure in the South African context. Although the use of a second analyst for the drawings would have improved the reliability of the interpretations, the interpretive tools remain western in their nature and all interpretations were, therefore, considered with caution.

4.4 Data collection

Data collection occurred in two separate interviews: one interview was conducted with the primary caregiver (PCG) of the selected child, and the other was conducted with the child (see Table 1 for the characteristics of the sample). Interviewing was selected as the form of data collection, as it was a natural form of interaction with participants, which allowed for the emergence of personal accounts and descriptions, in order to better understand the thoughts and feelings of the participants (Terre Blanche et al., 2006).

Although the purpose of the interviews was for research, it was considered to be important to follow a therapeutic interview process in which the client's needs were of foremost concern and in which an environment of trust and empathy was established (Sadock & Sadock, 2002). Great sensitivity to the comfort and vulnerability of the participants was exercised, bearing in mind the sensitive nature of the issues under investigation. Interviews were conducted in a safe

and private room with a “Do Not Disturb” sign on the door. This was within the clinic facilities in order to maintain a sense of safety and familiarity for the participants. In spite of the best attempts of the researcher to ensure that there were no disruptions, there were intermittent disturbances experienced. Disturbances took the form of interruptions by clinic staff to collect various items. Although these disturbances did not seem to damage rapport, it has been borne in mind during the analysis phase as a potential confounding factor.

Dyad	Child age	Child gender	Relationship of PCG to child	Age range of caregiver	Length of time on ART	Deaths mentioned	Knowledge of status
Dyad 1	9 yrs	Female	Aunt	Middle adult	4/5yrs	Mother	No
Dyad 2	8 yrs	Female	Grandmother	Older adult	Unknown	Nil	No
Dyad 3	8 yrs	Female	Mother	Middle adult	1 mth	Nil	No
Dyad 4	8 yrs	Female	Cousin	Young adult	4 mths	Nil	No
Dyad 5	11 yrs	Female	Sister	Young adult	4/5 yrs	Mother	No
Dyad 6	10 yrs	Female	Mother	Middle adult	5/6 mths	Nil	Yes
Dyad 7	10 yrs	Male	Aunt	Middle adult	2 wks	Both parents	Yes
Dyad 8	8 yrs	Female	Sister	Young adult	2 wks	Nil	Yes

Young adult: 18-35yrs, Middle adult: 35-50yrs, Older adult: >50yrs

Table 1: Characteristics of sample

Although the initial referral to the researcher was to be made by the doctor who was treating the child, it was important to obtain informed consent that was independent of the treatment personnel. Should informed consent have been obtained through the doctor or nursing staff, the participants may have felt obliged to co-operate, or may have felt that they did not have free choice in the decision-making process. It was also important that this critical research task was not handed over to someone who may not have been in a position to fully brief the potential participants. Thus, informed consent was obtained by the researcher, inside the interview room.

Consent was obtained verbally and in writing by the researcher prior to commencement of each interview (see Appendices F and G) Consent forms included consent from the caregiver regarding their and the child's participation (see ethical considerations below for a description of how participants were protected during the data collection process). All consent forms were available in English and *isiZulu* to ensure adequate understanding of the research process, and included consent for taping of the interviews. Questions were answered and the contents of the consent forms explained verbally in *isiZulu*, via a translator, to maximize the participants' understanding prior to commencing the interviews. The translator received a full briefing on the research purpose and process, and she was given a full project proposal, which she read through prior to the data collection.

Although it was the intention to conduct the interviews privately, on a one-on-one basis, with the caregivers, in four instances, the caregiver and child remained together in their interviews, at their own request. Bearing in mind the vulnerability of the population, it was decided that this would be allowed. The other four interviews were conducted privately on a one-on-one basis. The interviews were semi-structured (see Appendices B and C) and took approximately twenty-five to thirty minutes to complete. The second interview was conducted with the child who was receiving ARV treatment. The interviews were structured and included drawings (see Appendix D and E). The child interviews took approximately twenty to twenty-five minutes to complete. Field notes of observations made and questions raised during the interviews were taken, as were audio tape recordings. Photographs of the pictures drawn by the child participants were also taken to assist analysis. No photographs were taken of the study participants as this would have compromised their right to confidentiality and could have interfered with their ability to communicate freely.

The interviews were conducted in *isiZulu*, with the assistance of a translator. All tape recordings of the *isiZulu* interviews were translated and transcribed with the assistance of the same translator. The translator signed a pledge of confidentiality to ensure that she was fully aware of the ethical standards required of research (see Appendix H).

4.5 Data analysis

Once all information was in written form, thematic content analysis was utilized. As described by Terre Blanche and colleagues (2006), this process involved five major steps: familiarization and immersion, inducing themes, coding, elaboration, and interpretation and checking. Familiarization and immersion involved reading and re-reading transcripts until they became familiar, and themes naturally started to emerge. This then transitioned into the second stage which involved identifying themes which were relevant to the topic of interest. Coding occurred during and after the identification of themes when relevant and similar texts were marked and then grouped into meaningful pieces to analyse further. Once coded, the data was reread and explored in greater depth, and the coding system and themes altered accordingly. Once the information seemed to be revealing no further insights, a written interpretation of findings was made.

Issues of credibility, transferability and dependability were addressed by means of the following:

- **Credibility:** throughout the process of data collection and analysis, attention was paid to identify discrepant information. Discrepant views were examined for by conducting in-depth interviews which allowed for exploration where necessary. The use of drawings with the child participants was used as a form of triangulation, by confirming or disconfirming the understandings verbally expressed by the child. The drawings were studied for their content in relation to the questions asked (see Appendices D and E for further details).
- **Transferability:** throughout analysis and write-up of the findings, attention was paid to the specific context and circumstances of the study population. The findings aimed only to give insight and understanding into the experiences of a small group of individuals in a specific context without attempting to generalize across contexts.
- **Dependability:** in order to enhance dependability of the findings, clear reference was (and will continue to be) made to the methods employed to collect data, with

specific quotes being utilized where necessary to illustrate the context of the conclusions drawn.

4.6 Ethical issues

It was recognized throughout the research process that the participants of the study were a highly vulnerable group due to their age and HIV+ status. Therefore, every possible attempt was made to protect the participants at all stages in the study. Measures taken to ensure this included:

- The name of the clinic where the study took place not being disclosed at any point during the research process.
- No record of the clients' participation, or lack thereof, was documented in their files, a clause which was agreed upon by the clinic staff (see Appendix I).
- Written informed consent was obtained from the caregivers who participated in the study and from the caregiver of each child (see Appendices F and G). Once the potential participants had met the researcher and had the research further explained, they were given the opportunity to refuse or to withdraw. There were, however, no participants who did so.
- When obtaining the informed consent and assent, the audio recording of the interviews was fully explained.
- Verbal assent was obtained from each child participant before commencing the interview.
- At no point during the research process was the child's HIV status stated or referred to.
- All consent forms were available in English and *isiZulu* to ensure adequate understanding of the research process and requirements.
- At no point during analysis, transcription and write-up of the findings, has any identifying information been included. The only identifying information available was

that on the informed consent forms, which have been kept under lock and key with no information linking the forms to the project itself.

- The caregiver-child pairs were numbered sequentially, in order of interview (i.e. Dyad 1-8). This has been the only naming system utilized.
- There was no remuneration in cash or kind throughout the research process as the means for this did not exist. This was clearly stated before obtaining consent for participation.
- Provision was made for participants to discontinue their involvement in the interview at any time, had they so wished. The option to withdraw was clearly communicated to the participants at the start of the process. Had they so chosen to withdraw from the study, there would have been no negative consequences – however, this did not occur.
- All data acquired will be kept for the required period of five years, under lock and key in the research supervisor's office. Only the research supervisor will have access to the key. After the stipulated five-year period, written documents will be shredded and audio data will be incinerated on the same occasion.
- Feedback concerning the findings of the study will be given to the participants should they so desire, and a general synopsis of findings given to the hospital/clinic where the study occurred as per their request. The synopsis will however exclude any identifying information, or information which could have a negative impact on the clients and the care that they receive from the clinic.
- Dissemination of the results of the study will occur in the form of a presentation at the postgraduate conference, and possibly in the form of a paper.

Ethical clearance was obtained from the Higher Degrees Committee of the Humanities, Development and Social Sciences (HDSS) faculty (See Appendix J). The committee, however, placed certain conditions on the researcher. These included not having access to the medical file in order to obtain CD4 counts and history of the individual case circumstances. In addition to this, the duration of treatment and the specific regimen were excluded from the selection criteria. The researcher was also not permitted to discuss the child's diagnosis with the child

participants. The child's attendance at the ARV clinic was, however, taken as an indication that the child at least met the criteria for ARV treatment.

Ethical clearance was also obtained from the Department of Health (DOH). The proposal and HDSS clearance was submitted to the regional research office for the DOH. Clearance was granted by Dr S.S.S. Buthelezi on 18/06/2010, the Chairperson of the Provincial Health Research Committee for the KwaZulu-Natal (KZN) DoH (see Appendix K). Once permission was granted by the Department Research Committee, the data collection was allowed to begin at the site.

Chapter 5: Results, Discussion, Limitations and Recommendations

Data were collected in two separate interviews per dyad. One interview was conducted with the child, and one with their caregiver. The interviews were conducted on a one-on-one basis, but the results of all eight interviews will be presented in a synthesized manner. The results will be presented according to the themes which emerged during the analysis phase. The results of the caregiver interviews will be detailed first, followed by the findings in the child interviews.

5.1 Caregiver findings

5.1.1 Compliance as expected

According to the self-report of all eight interviewed caregivers, compliance was complete on all medications, all of the time. The method for report by caregivers was reported missed doses over the past four days. All eight interviewed caregivers reported that no doses had been missed in the previous four days. The caregivers were not, however, able to report the number of doses that had been given, presumably due to the complexity of the regime and the number of pills that are taken in the morning and evening being different. However, while it is possible that this may be an accurate report, it is important to note that self-report is known to be a relatively unreliable source of information about medication compliance, which has limited correlation with actual adherence, as evidenced when triangulated with other measures such as pill count, viral suppression, or medication return (Farley et al, 2008; Lyon et al., 2003). In this study, when seeking ethical clearance, certain constraints were placed on the researcher, and this prevented the accessing of patient files to evaluate compliance. For this reason, although the reported compliance should be viewed with caution, there is no alternative measure available.

A second important issue raised during the interviews, was an apparent discrepancy between reported compliance by the child as opposed to the caregiver. Although the caregivers

confidently stated that there were no missed doses in the past few days, and that all doses were given all of the time, a number of the children answered that they did sometimes forget their medication. The child participants commented that this happened when their caregiver forgot to tell them to take their medication. The child reports were not based on the number of doses taken and/or forgotten over the past four days; they were merely questioned whether they always took their medications and if they had taken them on the day of the interview, which required less detailed memory of the doses taken. This renews the need to view self-reported compliance with caution.

The issue of social desirability in the self-report by caregivers needs to be addressed at this point. It is possible that due to the interview setting being within the clinic, the caregivers felt that they needed to give the answers which would be expected by the medical staff to questions about compliance. Although the interviewees were assured that there would be no feedback to the medical staff about their specific answers, and that no answers would be considered wrong or right, it is still plausible that certain of the answers given – particularly regarding compliance – were the answers that they believed were expected rather than an accurate reflection of their adherence.

5.1.2 Familiarity and routine

“It’s not hard because she has become used to it. She knows that this medication is part of her life and that she cannot go without taking her medication. So she knows that in the morning she must take her medication and in the evening” *Aunt, Dyad 7*

Three of the eight caregivers reported that several doses were missed in the initial phases of treatment, but that this no longer occurs. This adjustment phase is supported in the literature (Dalal et al., 2008) and draws attention to the importance of early establishment of adherence. In this study, two important components of adjustment emerged: acceptance of the diagnosis and habit formation in treatment. A grandmother of one of the participants commented that she

was not used to it and had not accepted her grand-daughter's illness, but that as time went on, she got used to it. She now reports complete adherence.

Of the participants, two of the children had newly been placed on medication and in the interview with these children's caregivers it appeared that the adherence had not yet been established. These caregivers were unable to give correct amounts of the medication. One caregiver reported that there was some medication left over at the end of the month – which is a possible indicator of missed doses – as illustrated by the following quote:

“It's only been a month long, so I can't really say” *Mother, Dyad 3*

The role of familiarity and routine was well stated by one of the caregivers, who said that:

“It's not as hard as it was in the beginning; I have become used to it” *Grandmother, Dyad 2*

A further example of the role of routine establishment in the early phase of treatment was an instance where the child was commenced on treatment, but then her mother died, which disrupted the early adherence and clinic attendance. The caregiver reported in this instance that it took some time to return to the clinic and restart the treatment, but that the child had been on the treatment for the two weeks leading up to the data collection and had not missed any doses during this time:

“When we started she missed a few, but now we don't miss any doses. Her mom also passed away but now we don't miss any doses” *Sister, Dyad 5*

The caregivers identified various reminder strategies that they had managed to establish over time, with the predominant tool being the use of cell phone alarms as reminders. Another strategy utilized by the caregivers, was the use of certain television programs serving as reminders for the medication times.

“I now know that for example if there is a certain program on TV it means it's time for her medication” *Cousin, Dyad 4*

The following quotes from a number of the caregivers draw attention to the use of cell phones:

“What makes it easy is setting a reminder on my phone so that I don’t forget” *Aunt, Dyad 1*

“I set a reminder on my phone for seven o’clock so that when it rings I know it’s time to give her, her medication” *Grandmother, Dyad 2*

“I set an alarm on my cell phone” *Cousin, Dyad 4*

These memory strategies can be understood in Vygotskian terms as tools which assist in the mastery of the outside world (Hook et al., 2002). Initially, these tools may have been suggested to the participants by the clinic staff, but the claiming of these individual strategies in order to adapt them to personal context, shows the manner in which these processes become internalised. The child participants will be socialised to this process of remembering medications by their caregiver (i.e. interpersonal learning), thereby increasing their ZPD and equipping them with the necessary skills through mediation by their more knowledgeable caregiver.

5.1.3. Medication fatigue

Of the caregivers interviewed, six reported feelings of tiredness when needing to constantly remember to give the medication every day. Medication fatigue is a concept well documented in the literature around ART (Voss et al., 2006), and although not considered a leading cause of non-compliance, it is considered a significant determinant. The particular requirement to give the medication early in the morning was most frequently mentioned by the caregivers. There were a number of statements which showed in a very real and moving way, the fatigue induced by the constant need to remember to give medication at the same time every day, especially the early morning dose. Some of the most expressive quotes were as follows:

“It’s the time. I have to constantly watch the time, knowing that at six o’clock I must give it to her” *Aunt, Dyad 1*

“Sometimes I’m just tired and I fall asleep” *Mother, Dyad 3*

“Waking up in the morning, eish, but I wake up because I have to” *Sister, Dyad 8*

A factor which emerged as a possible mediator for this fatigue is the sharing of responsibility for administration of the medication. This factor has been raised in recent literature, and is spoken of as one of the significant reasons for the activation of sources of support (Merzel et al., 2008; Ncama et al., 2008; Parantham et al., 2009; Petersen et al., 2010). This support is both emotional and practical, and serves to reduce the burden of care on the PCG. Reducing the burden of care is also believed to be an important contributor to adherence (Merzel et al., 2008; Ncama et al., 2008; Parantham et al., 2009; Petersen et al., 2010), and this seemed to emerge from the interviews. Several of the participants mentioned the role of others in the household as significant, and this will be further explored in the discussion about support and silence in ART.

The process of teaching other members in the household about the medication and its administration is another example of mediated learning. In this instance however, the more knowledgeable other is the PCG who has attended the clinic and learnt from the clinic staff. It is thus evident that the ZPD of the caregiver has been enlarged to the degree that they have been able to internalise the complex requirements of the regimen and teach it to others.

5.1.4 Side effects

In both the child and caregiver interviews, it was found that side effects were seldom mentioned unless specifically asked about. It was also found that these side effects were only reported to have occurred in the early stages of treatment. The only side effects mentioned were decreased appetite, nausea, stomach aches and dizziness, dizziness being the only side-effect reported by a child participant. This finding stands in stark contrast to the findings in the literature which place poor palatability and side effects profiles as significant contributors to non-compliance (Glass et al., 2010; Lyon et al., 2003).

It is possible that there are certain cultural reasons, or parenting factors, which may account for this. African children may be expected to take medication regardless of palatability, as

obedience and respect for one's elders are valued goals in socializing children (Ramose, undated). It is also possible that the reasons for this lie in the high motivation to adhere exhibited by caregivers, a factor which will be explored in more depth in the later discussion concerning motivation and expectations around ART.

5.1.5 Knowledge

There were distinct differences between those participants who confidently understood the child's illness and the medications they were taking (n=2), and those who did not (n=3). Other caregivers tended to show very generic understandings of the illness, which lacked depth (n=3). Those who had good or fair understanding exhibited understandings of both the physiology of the disease and the action of the medication. There was, however, little correlation noted between caregiver characteristics (such as age-range) and the depth of the knowledge exhibited during the interviews. Examples of the categories will be given below, starting with what is considered a good understanding, then giving an example of a fair understanding, and then of poor understanding.

“I think if she takes it properly her viral load will drop, her CD4 count will increase...I think that it helps her by weakening the virus in her blood so that she can have a better quality of life” *Sister, Dyad 8*

“I think the medicine she gets strengthens her immune system” *Aunt, Dyad 1*

“The medication makes her very well and gives her a better quality of life” *Mother, Dyad 6*

Those with good knowledge reported that they had been taught everything they needed to know by the clinic staff. This is a highly commendable finding, as there is obviously a high degree of education occurring in spite of the resource-limited setting and large amount of pressure on the clinic system. This is also a very vivid example of the way in which learning on the interpersonal plane occurs. According to Vygotsky, constructive interpersonal learning leads to the successful internalisation of knowledge, incorporating it into the intrapersonal dimension. It is this process which seems to differentiate those with good knowledge and those with fair or poor knowledge.

Certain studies have attempted to explore the role of health beliefs in ART (Steele et al., 2001), but similar to this study (in which compliance is reported to be complete), such a link has not been clearly demonstrated. So whilst it cannot be concluded that the degree of knowledge held by the caregiver has an impact on compliance, a knowledge deficit was identified by the caregivers, as an ART associated difficulty. One of the caregivers who exhibited a limited understanding of the illness and its treatment, although not expressing many other difficulties, made the following statement in this regard:

“It’s hard to give someone else medication because they have so many questions about the medicine. I think that’s where it’s difficult.” *Aunt, Dyad 1*

Thus, continuing to educate and inform caregivers of the specifics of HIV and its treatment must remain a priority in order that the information can be effectively relayed to the child on treatment, as and when they seek out this information. Psychoeducation should also be provided to the child by the clinic staff in an age appropriate manner throughout the course of clinic visits (Department of Health, 2010).

5.1.6 Silence and support

Two distinct methods for handling the people around them emerged from the caregiver interviews. Some of the interviewees showed active eliciting of help and support from those around them, whilst others showed active avoidance of discussing the child’s status with those around them. Their approach to disclosure of the child’s condition to others did not, however, serve as an indicator of whether or not the child had been told about their HIV positive status. The role of social support has been the most documented determinant of compliance and its role is agreed upon throughout the current literature (Merzel et al., 2008; Ncama et al., 2008; Parantham et al., 2009; Petersen et al., 2010). This study also implicated social support as a significant factor in compliance in ART.

There were a number of reasons noted for the disclosure of a child’s status to other members of the family and community. There were a number of associated benefits experienced by the caregivers from this disclosure. None of the caregivers who had disclosed the child’s status to

others experienced negative responses to the child's illness. They reported that this allowed for a greater degree of assistance with adherence and support for clinic attendance, and continued compliance to the treatment. In this regard, the clinic attendees appeared to offer a high degree of support to one another and motivated each other to continue in the treatment programme. Examples of this are well illustrated in the following quotes taken from the interview data:

“...we encourage each other about the medication saying that we must get the medication because it's helpful in many ways. We also encourage one another in making sure we go to the clinic because they will help make life better than when we didn't have this medication” *Aunt,*

Dyad 1

“Some people say after they discovered they were sick, they started getting better and gaining weight. They were staying at home but then they had enough energy to go back to work and carry on with life” *Sister, Dyad 8*

“What I've heard from people is that I must carry on fetching the medication, that I mustn't stop so that the child can get better and that when I see the child getting better, I mustn't stop, I must carry on” *Mother, Dyad 6*

The support experienced by the caregivers following disclosure also seemed to have a significant impact on assistance in adhering to treatment, particularly with regards to taking all doses as prescribed. This sentiment was shared by a number of the caregivers:

“Sometimes I forget but someone reminds me” *Mother, Dyad 3*

“...usually everyone chips in. When it's nearly seven o'clock we remind each other” *Sister, Dyad 5*

“I told my family that both of us have this problem and that the pills are dangerous and we have to take them at the same time everyday so I am sure that my family will help because I have not hidden it from them. See, even if I am not there, I know that the family will be there to remind her about it because I explained everything to them” *Mother, Dyad 6*

In contrast to those who accessed social support for the illness and its treatment, those who did not, or considered themselves unable to, showed less optimism. It was unclear what the motivation for non-disclosure was, but it seemed that there was some degree of concern about

how other people would respond to the information. This possible fear-based code of silence, which according to the literature may occur as a result of the stigma associated with HIV/AIDS (Dlamini et al., 2009), does in some case prove to be valid in that stigma may negatively impact on the child and family.

Although few of the participants had experienced negative responses from people, those who had, found it a very difficult part of the ART experience. For example, the mother of an eight-year old participant experienced a negative response following the disclosure of the child's status. She found that in fact this lack of support, which she referred to as "tension in the family" as a result of the illness and treatment, was a barrier to adherence. It is therefore important that in such cases, alternative sources of support be sought out and activated for and/or by these caregivers, in order to improve the experience of ART and the degree of compliance.

Support through disclosure may improve adherence directly, but there may also be a more indirect pathway, which decreases compliance. This pathway may be the compromising of learning due to silence. From a Vygotskian perspective, speech is one of the most important sign systems humans use to master their behaviour and thoughts (Hook et al., 2002). If silence is enforced due to stigma, learning may be limited or compromised. An inability to question or relay information may therefore lead to decreased knowledge, and possibly decreased adherence as a result.

5.1.7 Disclosure and handing over of responsibility

According to the caregiver's reports, of the eight children interviewed, only three were aware of their HIV status. The other five did not have knowledge about their illness. The factors which prevented disclosure of the child's status to him/her varied, as did the age when the caregivers anticipate disclosing the child's status to him/her. Disclosure to the child of their status did not necessarily occur at the same time as handing over of medication responsibility – a process whose starting point appeared to be subjectively determined by the caregiver.

Disclosure of the child's status to him/her did not appear to be correlated to any other identifiable factors, and seemed rather to be determined by the caregiver's own beliefs about the child's readiness to know about their illness. It is also possible that the caregiver's own difficulties with acceptance of the child's illness, and their fears or concerns, are projected onto the child and presumed to be the way that the child will also feel, such as in the example below. Some of the reasons for non-disclosure to the child were as follows:

"...she's very afraid of this problem. She wrote a poem which showed me how afraid she is, so I didn't explain to her what's happening" *Aunt, Dyad 1*

"I think she is too young to know why" *Cousin, Dyad 4*

Avoidance of the topic and the use of an alternative illness as a reason for the medication, were the two most common ways of handling questions addressed to the caregiver by the child, as in the following instance:

"I say it's for her asthma because I think she is too young. Maybe she would get tired of taking the medication and stop it all together. So I say it's for her asthma in the hope that she will carry on drinking it" *Sister, Dyad 5*

Contrary to the findings in the literature that disclosure of the child's status may decrease adherence (Giacomet et al, 2003; Marhefka et al, 2006; Merzel et al., 2008), the study population did not seem to show this outcome. Those children whose status had been explained to them, in fact showed similar rates of compliance (by caregiver report). In the cases of both those who knew their status and did not know their status, age for disclosure and handing over responsibility were determined by the caregiver, based on subjective opinions about when the child would be ready to know about their illness. A differing factor between the participants who did not know their status, and those participants who did know their status, was that the children who knew their status were not expected to take responsibility for their treatment yet. In the other group, however, disclosure was seen to accompany handing over of medication responsibility. This is well illustrated by the following quote made regarding the age of disclosure:

"Maybe when she is thirteen years old and even then she may be able to come to the clinic on her own" *Grandmother, Dyad 2*

This is an important finding, because according to the literature (Giacomet et al, 2003; Marhefka et al, 2006; Merzel et al., 2008), one of the possible reasons for this decreased adherence with disclosure, is the handing over of responsibility for the medication simultaneously, at a time that the child may not be ready. Thus, it would seem that it is both effective and advisable that the handing over age be determined separately from the age of disclosure. It would, of course, remain to be seen how compliance is affected when the handing over of responsibility occurs, a question which this research did not attempt to answer.

In those cases where future disclosure and handing over of responsibility would occur simultaneously, the following cut-off points were identified by the caregivers: ten, twelve, thirteen, fourteen and eighteen years of age; “when I see that she has grown up”, or when it is decided and agreed upon by the family. These cut-off points appeared to some degree to be rather unstructured and somewhat random, and appeared to be associated with intelligence and/or maturity of the child as perceived or evaluated by the caregiver. In some cases, this disclosure and handing over of responsibility was expected to also include the commencement of independent clinic visits by the child (see previous quote).

Anticipated methods for disclosure and handing over of responsibility included the caregiver educating the child and/or the accessing of this education at the clinic. It was difficult to ascertain whether or not the caregivers viewed themselves as absolved from responsibility for education in the instances where the child received education from the clinic staff. This trust in the clinic staff and the accessing of the information available at the clinic are good indicators for success according to the literature (Ncama et al., 2008), and this process should therefore be encouraged where possible. The sense of security that this may offer to the caregivers is also notable and is again a commendation on the clinic utilized for the study. Vygotskian theory may offer useful insights into this process, both of when to hand over responsibility, but also the manner in which it occurs.

The work of Bibace and Walsh (1990) may be very useful in guiding this process of disclosure and handing over of responsibility for medication. Their work offers a theoretical framework which can assist in the nature of the mediation of the important information required for

adherence to be maintained. In this regard, the caregiver may benefit from guidance which is based in theory.

5.1.8 Expectation and motivation

A further important factor which had a bearing on compliance, and which emerged from the data, is the expectations that the caregivers had about the medication and the resulting degree of motivation to comply, that they experienced. Their expectations and motivation seemed to be important contributors to the degree of adherence. In order to illustrate this, a number of direct quotes will be utilized, as they show both the cognitions and means of constructing ART by the caregivers.

“...the medicine seems to help. Her mom was sick when she got the medicine, she got better, and this motivated me to bring her to the clinic. I can see that they are helping her and that gives me motivation, because if she doesn't [take the medication] she may fall sick again, so I must try to get the medicine so she can be well.” *Aunt, Dyad 1*

“I think it's because this is the only way she will have life” *Aunt, Dyad 1*

“I think she will get better.” *Aunt, Dyad 1*

“I've seen an improvement in that if she falls sick it's not like it was before. She gets better easier” *Grandmother, Dyad 2*

“I am motivated by the difference I see in the child, because I see a difference in the child from when she started to now” *Grandmother, Dyad 2*

“I think she will get better and be like other kids. You will not be able to see that something is wrong with her” *Sister, Dyad 5*

“There was a problem because her mother was not taking the medication and she passed away. When the mother passed away, we noticed that she started losing weight. She started taking the medication and we saw a marked difference” *Sister, Dyad 5*

“I think it's important because it will allow my child to have a long life and become healthier”
Mother, Dyad 6

“I think she will get better and better, just as she has been getting better and better since she started taking the medication. I can see a difference in her” *Mother, Dyad 6*

“Before there were ARVs, it was tough, but since using ARVs, we have been helped a lot and we are able to carry on with life because of this medication” *Sister, Dyad 8*

As evidenced by these quotes, many of the caregivers express a motivation derived from witnessing the improvements of those on ART (or the deterioration of those who were not). However, it is not possible to conclude whether this motivation will persist indefinitely. For this reason, as suggested by Steele and Grauer (2003), longitudinal studies and long-term and/or continuous evaluation of adherence is essential. Factors which impact upon adherence will change over the life course of treatment. These findings should be seen only as potential insights into the current functioning of this group of individuals.

5.1.9 Access difficulties

A number of studies (for example Davies et al., 2009) have confirmed that optimum adherence is possible in resource-limited settings, but it must be acknowledged that in such contexts, the barriers to access are significant. Studies in South Africa (Rosen et al., 2007) have shown that although treatment is free, the costs incurred in attending clinic appointments and maintaining sufficient nutrition (as prescribed with ART) are substantial, and in many cases, unmanageable. The predominant finding in this study was that the cost of transport to the clinic was a source of constant concern, which required significant planning and saving throughout the month. Again, there were a number of very moving and very real descriptions by the caregivers of some of these challenges:

“Sometimes I have transport problems but I will budget to make sure we have money for the trip to the clinic” *Aunt, Dyad 1*

“Sometimes there won’t be enough money but there is no way that I can miss an appointment” *Grandmother, Dyad 2*

“Sometimes it’s difficult in terms of transport but I make sure I get here” *Cousin, Dyad 4*

“Sometimes it’s a toss-up between spending money on food and transport because the child has to eat. So I’m often trying to find money to get here” *Sister, Dyad 5*

“It’s hard to give a child medicine when they are hungry” *Sister, Dyad 5*

“Sometimes it’s difficult because I don’t work, but I try my best to collect money here and there to make sure I get here” *Mother, Dyad 6*

“It can be difficult because I come from [name of district approximately 80km away] but they’ve made it easier in that there is now a bus that transports us every Monday. We go to our clinic, and we book, but if you don’t book, you’ll lose your spot on the bus because it will be full” *Aunt, Dyad 7*

“...sometimes there is no money for transport. To get here we need to take two different kombi’s and sometimes there just isn’t enough money for it” *Sister, Dyad 8*

There is little doubt that these barriers to access have the potential of profoundly impacting on adherence. If there is little food to give the children who are on treatment, and no money to attend the clinic, it is highly probable that the compliance may drop below the acceptable levels delineated in the literature (Diiorio et al., 2009). It must therefore be noted that where possible, consideration be given to these difficulties which impede access. The provision of ART in the rural clinics (which is currently in progress) should remain a priority, as should appropriate access to financial resources (such as social grants). The management of HIV/AIDS in a manner which will maximize the chances of effective ARV compliance should, therefore, be holistic and multi-disciplinary in its approach.

5.1.10 Responsibility for medication

The interviewed caregivers were all close relatives or members of the child’s extended family. It was evident that in fact a number of the children were being taken care of by members of their extended families rather than their parents. The relationships of the caregiver to the child included: sisters, mothers, grandmother, cousin and aunts. In three cases, there was specific mention of the death of the child’s parent/parents, which then resulted in the responsibility for

the child's care falling to the next able relatives. These caregivers would also be grieving the death of their family member.

The responsibility and burden of caring for an HIV positive child and managing their medication, is significant. In spite of this, however, of the interviewed caregivers, regardless of their relationship to the child, all expressed a willingness and dedication to caring for the child. This may be a result of the cultural construction of family: the African tradition of collective responsibility for rearing of children (Ramose, undated). The result is that the children interviewed are receiving care and treatment assistance from caregivers who appear to be devoted to them and their well-being.

The responsibilities for caring for these children include:

- constant monitoring and administration of medication
- clinic attendance
- planning for transport-related treatment costs
- worry over future health status
- provision of care for the child
- care for the child in the event of their moving away, or death
- ongoing support for the child in the event of the death of their parents

These challenges and responsibilities have the potential to decrease the standard of care that the child receives, and their access to treatment. They should, therefore, be viewed seriously, and wherever possible, the caregivers assisted, in order to improve the outcomes of these children.

5.1.11 Summary of findings

Although it was difficult to determine the degree of accuracy of the self-reported compliance, there were a number of significant findings regarding compliance on ART which emerged from the caregivers of the HIV/AIDS infected child participants. Factors which appeared to contribute to improved adherence included:

- social support and shared responsibility through disclosure of the child's status to significant others
- high expectation and experience of positive outcomes of ART
- establishment of routines

On the other hand, those factors which had the potential to negatively impact on compliance on treatment were:

- life stressors
- economic difficulty
- stigma and isolation
- regimen fatigue

5.2. Child findings

5.2.1 Child reported adherence

As mentioned in the previous section, self-reported compliance has been found in the literature to be a poor estimate of actual adherence (Lyon et al., 2003). The reported compliance is therefore viewed with some degree of caution – an assumption given some support by the discrepant reports of compliance between caregivers and children. While few caregivers reported missing doses (except at the beginning), the child participants confessed to forgetting

their medication from time to time – usually as a result of their caregiver forgetting it. Whether or not the doses were given in spite of the child forgetting them, is difficult to determine, however, it should be understood that caregiver-reported compliance in this study may be higher than actual compliance.

5.2.2. Disclosure

The child participants fell into two groups – those who knew their status (n=3) and those who did not (n=5). Those children who were aware of their status and/or active participants in their treatment showed more in-depth answers to the questions asked regarding their treatment, compared to those children who were unaware of their status. A number of other qualitative differences between these two groups emerged (see Figures 1 and 2 for a synthesis and comparison of drawing findings) and will be discussed.

As has been mentioned, contrary to the literature finding that disclosure of the child's status decreases adherence (Giacomet et al, 2003; Marhefka et al, 2006; Merzel et al., 2008), children in this study who were aware of their status showed better adaptation to their treatment and better knowledge regarding the action of the medication and the need to continue taking it. They also reported similar rates of adherence. It must, however, be noted at this stage in the discussion that the sample group was small and the findings are not intended to be generalized across contexts.

5.2.2.1 Participation or invisibility

The data gleaned from the drawings of the two groups of children mentioned above (see Appendix L for samples of the pictures), showed some differences in their interpretive content in this regard (see Table 2 for a summary of Koppitz emotional indicators present in the drawings). Of the three children who knew their status, two drew themselves in the pictures coming to the clinic (i.e. 67%), as opposed to only two out of five (40%) of the children in the group who were unaware of their status. This proportional discrepancy may be a result of the

children misunderstanding the instruction to draw a picture of themselves *and* who they came with to the clinic. However, there may also be an alternate meaning, that the children who know their status have a proportionately greater sense of agency in the process of managing their illness – including clinic visits.

If this hypothesis is correct, it would be advisable that information concerning the child’s status be given to him/her, to increase their sense of agency in their treatment, as well as their personal experiences associated with treatment. Also, if the findings of this study are correct, in that disclosure of the child’s status does not seem to reduce adherence, then there remains an overall benefit for disclosure. These hypotheses would, however, require further exploration over time, as they remain very tentative given the small sample size.

DYAD	WHAT	WHO	EMOTIONAL INDICATORS	POTENTIAL HYPOTHESES
Dyad 1		Caregiver	Small drawing	Withdrawal, shyness, insecurity, timidity and depression
Dyad 2	“Flower, a birthday person, love, a star and a present”	Self and caregiver	Shaded face	Severe anxiety, very poor self-concept
Dyad 3	House and flowers	Caregiver	Small drawing No mouth Short arms No hands Disintegration	Withdrawal, shyness, insecurity, timidity and depression Anxiety, insecurity, withdrawal, poor communication and possible respiratory concerns Withdrawal, introversion, timidity Inadequacy, guilt over failures and/or inabilities Aggression
Dyad 4	Soccer Ball	Caregiver	Small drawing	Withdrawal, shyness, insecurity, timidity and depression
Dyad 5	South African Flag	Self and caregiver	Small drawing Long arms No hands	Withdrawal, shyness, insecurity, timidity and depression Aggression Inadequacy, guilt over failures and/or inabilities
Dyad 6	Friends	Self and caregiver	Short arms No hands	Withdrawal, introversion, timidity Inadequacy, guilt over failures and/or inabilities
Dyad 7	Truck	Self and caregiver	Teeth Long arms	Aggression Aggression
Dyad 8	Self going to school	Caregiver	Small Long arms	Withdrawal, shyness, insecurity, timidity and depression Aggression

Table 2: Summary of drawing findings

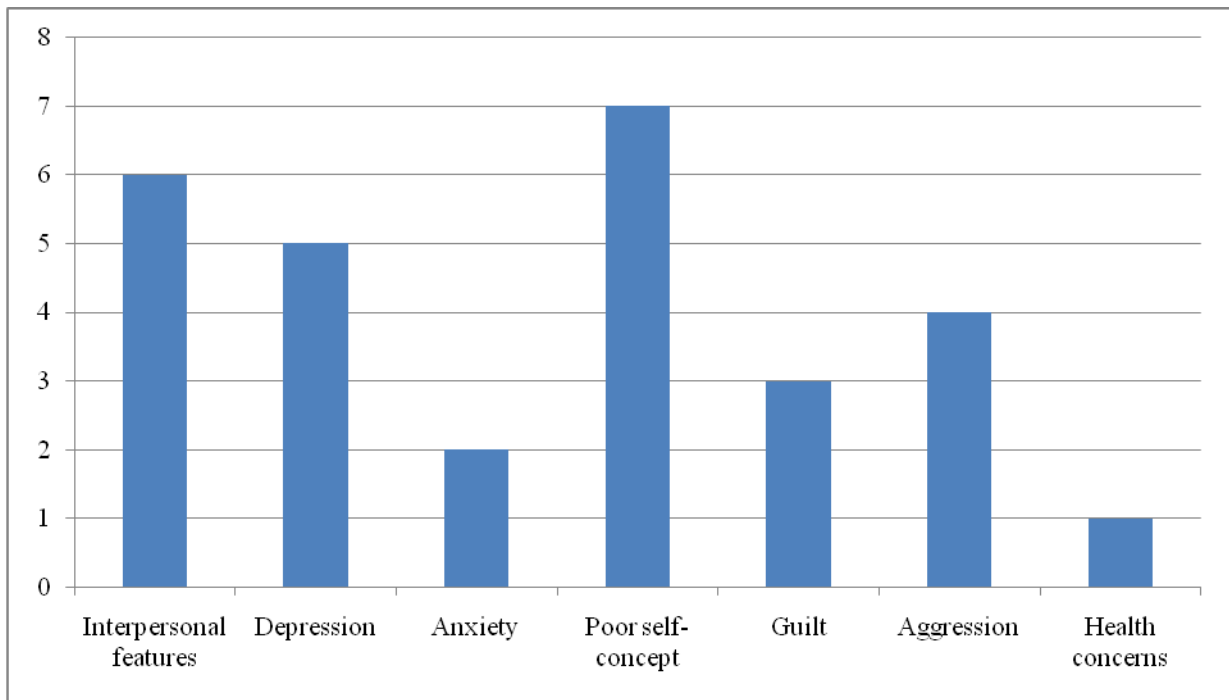


Figure 1: Synthesis of findings of drawings in relation to Koppitz's (1968) interpretative hypotheses across the full sample of 8 children

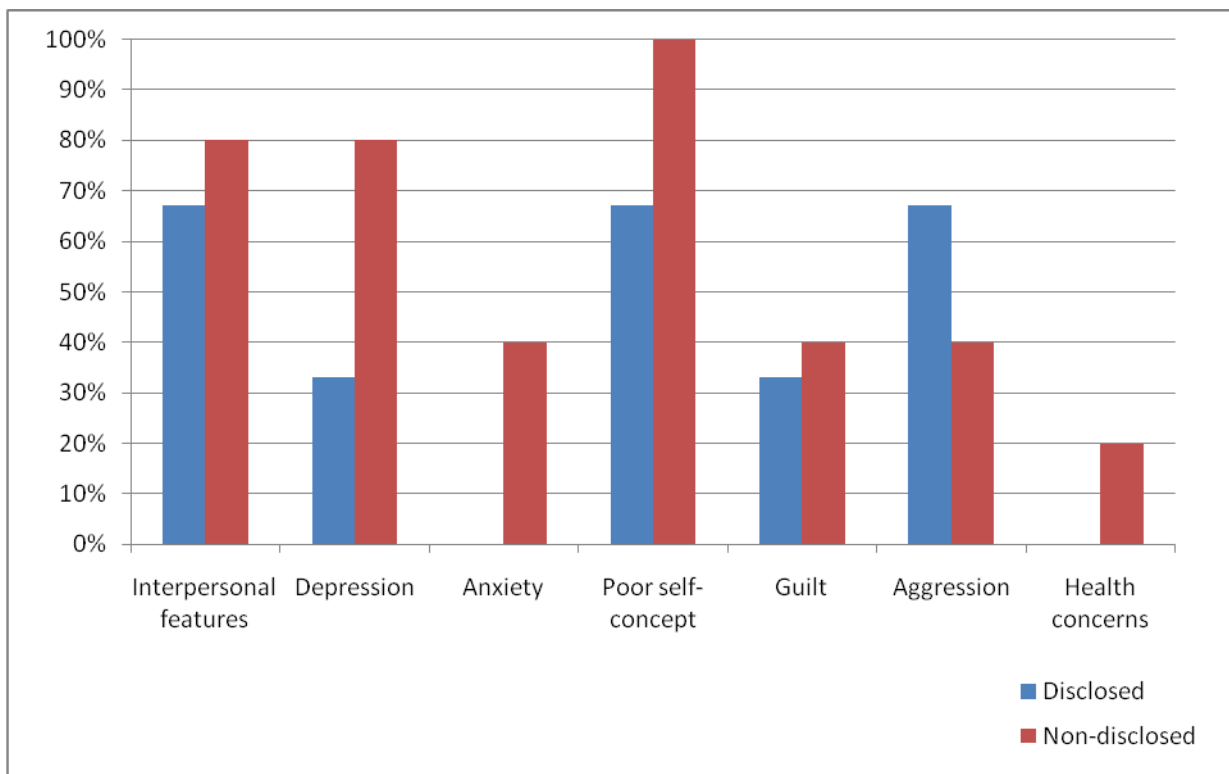


Figure 2: Proportional comparison of findings for disclosed and non-disclosed individuals

5.2.2.2 Interpersonal indicators associated with disclosure

Some interpersonal indicators associated with disclosure (or lack thereof) were identified using the drawings done by the child participants. The label ‘interpersonal features’, was given to a number of emotional indicators with similar implications on the child’s interpersonal functioning. These indicators were: withdrawal, shyness, timidity, poor communication, and introversion.

There were a proportionately higher number of children (80% compared to 67%) who were unaware of their HIV positive status (forthwith termed non-disclosed), who showed the presence of indicators of an interpersonal nature. These children therefore showed comparatively higher degrees of withdrawal, shyness, timidity, poor communication and introversion. Whilst this is not necessarily indicative of larger populations, it is possible that within this small sample group, ignorance of their status leads them to internalize hostile or ambiguous responses from the people around them, who know the child’s status. Alternatively, they may lack confidence in themselves due to feeling different to the people around them as a result of having to take medication which they do not understand.

Although interpersonal indicators were also present in those children who knew their status, they occurred in a proportionately lower degree. It is possible, therefore, that their experience of having their status disclosed to them has improved their relationships and communication with their caregivers. It may also have exposed them to the same degree of support experienced by the caregivers in the previous discussion, therefore decreasing their social fears and their avoidance of social contexts and relationships.

5.2.2.3 Intrapersonal indicators associated with disclosure

In addition to the interpersonal indicators associated with disclosure, there were a number of intrapersonal indicators which were also identified. These factors included: depression, anxiety, poor self-concept, guilt, aggression, and health concerns. These findings occurred in varying

degrees amongst the child participants. All of these indicators occurred in a higher proportion amongst the non-disclosed children, with the exception of aggression, which occurred in a higher proportion amongst the disclosed children (67% compared to 40%).

The first and most significant finding was the absence of anxiety and health concerns amongst the disclosed children. In comparison to the non-disclosed children who showed the presence of indicators for anxiety and health concerns (40% and 20% respectively), disclosed children did not show either of these indicators at all. It is possible that the higher degree of anxiety and concern around health in the non-disclosed group is of some significance. The children who are unaware of their status may have serious concerns about what is making them ill and not knowing this may in fact be a source of anxiety. The continuous requirements to take tablets (which are associated with sickness) may also be alarming for these children, as they have no understanding of why they have to take the medication. According to Bibace and Walsh (1980, 1990), although these children may not have the capacity to fully grasp the nature of their illness, appropriate explanations about the need for medication, or the reason for their sporadic bouts of sickness, may relieve some of this anxiety.

Another important finding amongst the non-disclosed children is that they also exhibit higher proportions of depression and guilt. It has been found in literature that depression has a potentially negative impact on adherence to ARVs (Diiorio et al., 2009; Glass et al., 2010; Lyon et al., 2003), and therefore, it is significant that the depressive tendencies present in the non-disclosed group were markedly higher than in the disclosed group (80% compared to 33%). Since depression is a known contributor to compliance, it is a concern that depressive tendencies are present in the group who are unaware of their status. It is, therefore, another important finding which can motivate for disclosure of status to the HIV positive children on treatment.

The proportions of guilt feelings present in the two groups were not as different as some of the other indicators. They were, however, still slightly more prevalent in the non-disclosed group (40% compared to 33%). The presence of these feelings was not associated with reported deaths or any other identifiable factor. Bearing this in mind, it is possible that the similarly

occurring guilt feelings are a function of these children's perceptions of themselves as burdens, or as deserving in some way of the tablets. However, these are summations which would require further investigation.

A factor which may be linked to the guilt feelings mentioned above, and to the interpersonal indicators, is poor self-concept. For the purposes of categorisation, indicators of poor self-concept included insecurity, inadequacy and poor self-image. Poor self-concept, like interpersonal indicators and guilt feelings, was also present in higher proportions in non-disclosed individuals. This is possibly due to the uncertainties that these non-disclosed children experience in their interpersonal relationships, their decreased health status which they do not understand, and their feelings of being different or somehow deficient due to their medication. The most interesting aspect of this finding, however, is that whilst two out of three (67%) of disclosed children showed these indicators, all of the non-disclosed children (i.e. 100%) of non-disclosed showed these indicators. This difference would also require further investigation in order to clarify the exact nature of its relationship to disclosure.

The final intrapersonal indicator which requires explanation and exploration is that of aggression. This was the only finding which showed a higher proportion amongst disclosed children (67% compared to 40%). It was not clear, however, whether this aggression was inward directed or overt, as there was no history obtained in this regard. A possible way, in which the increased aggression can be understood in this group, is that the children are experiencing feelings of hostility toward the people who gave them the disease, or toward their PCG's for forcing them to take medication which reminds them daily of their illness. An alternate explanation is that the aggression is a symptom of other emotions which are masked, namely fear or sadness. Finally their aggression may be linked to a sense of injustice at their illness, although this would likely be beyond their developmental conceptions of illness (Bibace & Walsh, 1980).

5.2.2.4 *Knowledge and disclosure*

In both the child interview data and the gingerbread man drawings done by the child, there were few examples of understanding of the medication they were taking, or of the disease with which they were infected. There was, however, some degree of understanding shown by individuals who knew their status. Whilst the child participants who were unaware of their status (with the exception of one child who is taken care of by her sister and has been on treatment for 4-5 years) gave generic answers to the questions asked about their medication, those who knew their status were able to give novel explanations with little difficulty. Some examples of these explanations included the following quotes:

“...the medication goes everywhere in my body...it makes sure I stay alive... (I feel good) that I’m not sick anymore and that I’m not coughing anymore” *Child, Dyad 6*

“What I like about this medication is that it helps my blood...I think once the medicine is inside it makes my blood go faster” *Child, Dyad 7*

In the above quotes, the children are able to make sense of their illness and their medication in ways which are developmentally appropriate and provide both a sense of stability, but also motivation to continue taking the medication. This concept has been documented by Bibace and Walsh (1990). This knowledge may be seen, at this stage, to have a positive impact on the child’s adherence, but in order to determine the long-term impact of knowledge and its role in adherence once responsibility is handed over, further studies would need to be conducted.

5.2.3 **Summary of child findings**

The data which emerged from the child participants was gleaned from two different sources, projective drawings, and interview data. Firstly, there were differences identified between caregiver report of compliance and child report of compliance, with child participants giving possible evidence of lower compliance than caregivers. The reliability of this report should, however, be viewed with caution.

The second important finding was that there were qualitative differences noted between disclosed and non-disclosed children. According to Koppitz drawing analysis there were a number of emotional indicators which occurred in a higher degree amongst non-disclosed children and are significant indicators of these children's experiences of their medication. There was only one indicator present in a higher degree amongst disclosed children and in this regard, the findings of this study seem to show that there is an overall benefit to disclosure.

5.3. Summary of findings

A number of factors which have an effect on compliance have been identified in both the child and caregiver interviews. These findings include psychosocial determinants as well as barriers to access and emotional impacts of treatment. These factors have been explored from the child and caregiver's perspectives and have in some cases confirmed literature findings to date. In other cases, they have added specific meaning to these factors as they are experienced in the specific context of this study. The findings can be utilized to make recommendations which may be implemented at the clinic level, and to inform future studies on a similar population.

5.4 Limitations

There were a number of limitations in the study which will now be explained briefly. Firstly, a significant factor which may have had a bearing on the findings is the use of an interpreter. The sample population were predominantly *isiZulu* speaking and thus there was a need for an interpreter from English to *isiZulu* during the interviews and then from *isiZulu* to English in the transcription phase. The use of an interpreter enabled, as far as possible, the correct conveyance of meaning and actual experience as it was described by the participants. Although the interpreter was thoroughly briefed on all aspects of the study, it is possible that some of the intended meaning of questions and/or answers may have been lost in the process. The interpreter utilized in the interviews was also utilized in the transcription in order to minimize loss of meaning. However, there remains the possibility that the use of an interpreter had an influence on the findings of the study.

Secondly, the sporadic interruptions experienced during three of the interviews may also have had a bearing on the findings of the study. Although every possible attempt was made to avoid this, the setting used for the interviews was within the selected clinic, and as such, interruptions were difficult to control and somewhat inevitable due to the demand on the rooms within the clinic. Although a “Do Not Disturb” sign was utilized, there were a number of interruptions during the interview process, of varying lengths and distraction. It is difficult to ascertain the extent of the damage done by such interruptions; however, it should be borne in mind when considering the findings.

Thirdly, during the interview process, three of the caregivers were reluctant to have the child sit alone outside in the queue, and one of the children did not wish their caregiver to leave them. Due to the age and vulnerability of the child participants, these children were allowed to stay in the room during the caregiver interview. Similarly, the caregivers of these children stayed in the room during the child’s interview. Attempts were made to keep the children distracted during the caregiver’s interview through the use of drawing materials; however, distraction of the caregiver was not easily accomplished during the child interview. Once again the extent and nature of the damage done by this is difficult to quantify.

Fourthly, the use of drawings is believed to have been helpful. However, it must be noted that some of the child participants were unsure of the instructions and expectations of the ginger-bread man pictures intended to measure their degree of understanding about their medication and their experience of it. For this reason, the ginger-bread man pictures drawn have been utilized only in conjunction with verbal messages and the other pictures, to avoid over-interpretation of a potentially flawed data collection method.

A fifth issue which may have had an impact on the findings is that the ethical restrictions imposed on the study prohibited the use of the patient files for collateral information, through the use of alternate measures of adherence. Thus the self-reported compliance should be viewed with some caution. This requires that the findings be viewed in the light of the fact that they have been based on the high self-reported compliance. Lastly, the time pressure placed on

the research process should also be noted, as the depth and quality of the findings may have been compromised to some degree in order to meet the required deadlines.

5.5 Recommendations

There are two sets of recommendations which can be made: those for further studies, and those which can be utilized to inform management within the clinic.

For further studies:

- Further studies to ascertain levels of adherence to other aspects of ART schedule e.g. diet and time between doses (Schonnesson et al., 2006).
- Further studies on the reasons for and frequency of missed doses in order to tailor interventions to those specific factors (Steele & Grauer, 2003).
- Development of models of adherence (Steele & Grauer, 2003)
- Further examination of the applicability and possible contribution of Vygotskian theory of interpersonal learning to understanding adherence and factors which mediate learning of adherence behaviours.
- Further studies on this population which allow for detailed information to be gained concerning compliance, using measures other than self-report, as this will add depth to the current findings.
- Further studies on the possible benefits of disclosure of status to infected children.
- Follow-up on the compliance of this population as they reach adolescence and increasingly take responsibility for their own medication.

For improved management within the clinic:

- Continued emphasis on building trust and rapport with the clinic attendees, although there is evidence of a well-managed programme in which there is a high degree of education given to attendees.

- Increased disclosure of the status of the child to him/her, in order to maximize the possible benefits in respect of adherence as evidenced by the findings of this study, and according to the government protocol (Department of health, 2010). This process may be managed by the caregivers, but the assistance of the clinic staff in this process would be both advisable and useful.
- Possible use of psychological intervention to improve the intra- and interpersonal effects and experiences of HIV status on the individual child and caregiver, in order to improve the potential outcomes of these individuals.

Chapter 6: Conclusion

HIV/AIDS is a chronic disease with no identified cure. However, ART has offered the most significant chance to improve the quality of life and the prognosis of those infected with HIV/AIDS. In order for the benefits of ART to be maximized, a high degree of compliance is necessary, but there are a number of factors which may affect compliance that need to be explored. The factors, which offer possible insights into improving compliance, are as important to determine as those factors which are barriers to adherence – this was one of the important aims of this study.

The aims of the study were explained at the beginning of this dissertation and were followed by a review of the current literature and findings in the HIV/AIDS and ART arena. The methodology was then described and the results presented and discussed in the light of the current literature. A Vygotskian frame has been utilised where possible throughout this process to improve insight into the nature of the mediated learning process of adherence. The limitations of the study were then clearly delineated and some recommendations were made, based on the findings. There were a number of factors that emerged in the process of this study, which may add important insight into the process of ARV compliance if further explored.

Chapter 7: References

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Appendices

Appendix A

Tablets



Abacavir (ABC)



Lamivudine (3TC)



Efavirenz (EFV)



Stavudine (d4T)



Zidovudine (AZT)

Appendix B

Interview schedule – Adult caregiver

Practical aspects

1. What is your relationship to the child whom you have brought to the clinic today?
2. Is this the only child that you bring to the clinic?
3. Do you find it difficult to get to the clinic appointments?
 - a. If yes, why is that?
 - b. If no, what makes it easy for you to get here?

Medication related knowledge

4. Why do you think you have to come to the clinic?
5. Describe to me what medication you give, and when and how you give the medication to the child (what does it look like, number of tablets/amount of syrup, frequency).
6. Does the child know why they have to take the medicine?
7. Do you know why the child has to take the medicine?
8. Why do you think that you need to give the child medication?

Remembering medication

9. Who gives the medication to this child every day?
10. What makes it easy and difficult to remember to give the medication every day?

Medication related experiences

11. What is it like giving the medication?
 - a. What makes it difficult?
 - b. Why is it easy?
12. Does the child take his/her medication well?
 - a. If yes, is this all the time? And why do you think they take the medicine well?
 - b. If no, is this all the time? And why do you think they don't take the medicine well?

Compliance

13. In the last four days, how many doses have you given the child?
14. In the last four days, how many doses has the child missed?
 - a. What happened to cause the doses to be missed?
 - b. Does this often happen?

Medication action and purpose

15. What do you think will happen if the child takes the medicine?
16. What do you think the medication is doing to the child's body?
17. What do you think will happen if the child doesn't take the medicine or if they stop taking the medicine?

Challenges, difficulties and coping

18. What is it like having to manage the child's medication and clinic appointments?
 - a. What is stressful about it?
 - b. How do you manage to cope with the demands of it?

19. Are there other aspects of your life which make giving the medicine and coming to appointments difficult?

Social support

20. Is there anyone else in your home that has to take the same medications?
21. Is there anyone else in your home that has to take other medications?
22. Do the other members of your household know what the child's medication is for?
 - a. If yes, how do they handle that?
 - b. If no, what do you tell them instead and why do they not know?
23. Do your friends and neighbours know why the child takes the medicine?
 - a. If yes, how did you tell them? And how do they treat you and the child as a result?
 - b. If no, what do they think the medicine is for? And what makes you not want to tell them about the child's illness?
24. Who else helps with giving the medication?
25. Describe to me some good responses that you've had from people about your child's medication.
26. Describe to me some of the bad responses that you've had from people about the medication.

Medication fatigue and stress from responsibility

27. Do you ever get tired of having to remember and give the medication to the child?
28. What worries you most about the medication?
29. What worries you most about the child's illness?
30. Does the child ever ask you questions about the medication?
 - a. If yes, what kinds of questions? And how do you answer them?
 - b. If no, what do you tell the child about the medication?

Handing over the responsibility for medication

31. When do you think your child will be able to be responsible for taking the medication?
32. How will you decide the right timing?
33. What will you teach the child about the medication when they start taking it over for themselves?
34. How will you ensure that they are taking the medication correctly?

General and closing

35. Is there anything you would like to ask me about the medicine that the child is taking, or anything else you would like to tell me about the medicine and giving the medicine to the child?

Appendix C

Interview schedule – Adult caregiver (isiZulu)

Izimo esibhekana nazo

1. Ngabe una budlelwane buni nomntwana omulethe lapha emitholampilo?
2. Ngabe yilona kuphela umntwana omuletha lapha emitholampilo?
3. Ngabe ukuthola kunzima ukufika emitholampilo ngezinsuku osuke unqunyelwe zona?
 - a. Uma kungu yebo, kungani?
 - b. Uma kungu cha, yini eyenza kube lula ukuba ufike lapha?

Ulwazi ngemithi

4. ucabanga ukuthi kungani kufanele uye emitholampilo?
5. ngichazele ukuthi imiphi imithi oyinikezelayo umntwana, nini nokuthi uyinikezela kanjani imithi? (Ngabe ibukeka kanjani, inombolo yamaphilisi, inani lomuthi ophuzwayo nangokuphinda phinda).
6. Ngabe uyazi yini umntwana kungani kumele adle imithi?
7. Ngabe wena uyazi ukuthi kungani umntwana kumele adle imithi?
8. Uzabanga ukuthi kungani umntwana kumele adle imithi?

Ukukhumbula imithi

9. Ngabe ubani unikezela umntwana imithi nsuku zonke?
10. Yini eyenza kubelula noma kube nzima ukukhumbula ukunikezela imithi nsuku zonke?

Ulwazi olumayelana nemithi

11. Ngabe kunjani ukunikezela omunye umuntu imithi?
 - a. Ngabe yini eyenza kube nzima?
 - b. Ngabe kungani kube lula?
12. Ngabe umntwana uyidla kahle imithi?
 - a. Uma kunguyebo, ngabe uyidla ngezikhathi zonke? Futhi kungani ucabanga ukuthi uyidla ngendle imithi umntwana?
 - b. Uma kungu cha, ngabe uyidla ngezikhathi zonke? Futhi kungani ucabanga ukuthi akayidli kahle imithi umntwana?

Ukuvumelana kahle

13. Ezinsukwini ezine ezedlule, ngabe lingakanani inani lemithi aseydilile umntwana?
14. Ezinsukwini ezine ezedlule, ngabe lingakanani inani lemithi alidlanga umntwana?
 - a. Ngabe yini eyenze ukuba ingathathwa imithi?
 - b. Ngabe lokhu kuvamile ukwenzeka?

Inhloso kanye nokusebenza kwemithi

15. Ngabe ucabanga ukuthi yini ezokwenzeka uma umntwana ethatha imithi?
16. Ngabe ucabanga ukuthi imithi yenza msebenzi muni emzimbeni womntwana?
17. Ngabe ucabanga ukuthi kuzo kwenzakalani uma umntwana eyeka ukuthatha imithi noma eyeka ukudla imithi unomphela?

Inselela, ubunzima kanye nokubhekana nesimo

18. Ngabe kunjani ukuphatha imithi yomntwana kanye nokuhambela izinsuku anqunyelwe zona ukuvakashela emitholampilo?
 - a. Ngabe ibuphi ubunzima ngalokhu?
 - b. Ngabe wenza kanjani ukuze ukwazi ukumelana nezidingo zalokhu?
19. Ngabe zikhona izimo obhekana nazo empilweni yakho ezenza
20. ukunikezela imithi umntwana kanye noku vakashela emitholampilo ngezinsuku ezinqunyiwe?

Ukusekwa ngabanye abantu

21. Ngabe ukhona omunye umuntu ekhaya lakho othatha imithi efanayo nale oyisebanzisa enganeni?
22. Ngabe ukhona omunye umuntu ekhaya lakho othatha imithi ehluke kunalena oyisebanzisa enganeni?
23. Ngabe ayazi yini amanye amalunga omndeni ukuthi eyani lemithi esetshenziswa umntwana na?
 - a. Uma kungu yebo, ngabe bamelana kanjani nalento?
 - b. Uma kungu cha, ngabe ubatshele ukuthi eyani futhi kungani kumele bangazi ngalokhu?
24. Ngabe abangani nomakhelwane bakho bayazi ukuthi kungani umntwana wakho ethatha imithi?
 - a. Uma kungu yebo, ngabe ubatshele kanjani? Futhi bakuphatha kanjani wena nomntwana wakho njengo mphumelo?
 - b. Uma kungu cha, ngabe bacabanga ukuthi ngeyani imithi? Futhi ngabe yini eyenza ukuthi ungabatshele ngokugula komntwana?
25. Ngabe ubani omunye okusiza ekunikezeleni umntwana imithi?
26. Ngichazele ngezimpundo ezinhle ozitholile kubantu mayelana nemithi edliwa umntwana wakho?
27. Ngichazele ngezimpundo ezimbi ozitholile kubantu mayelana nemithi edliwa umntwana wakho?

Ukukhathala nokukhathazeka ngobhekelela ngemithi

28. Ngabe kuyenzeka ukuthi ukhathazwe ukukhumbula kanye nokunikezela imithi umntwana?
29. Ngabe yini ekukhathaza kakhulu ngale mithi?
30. Ngabe yini ekukhathaza kakhulu ngokugula komntwana?
31. Ngabe uke akubuze yini umntwana ngale mithi?
 - a. Uma kungu yebo, ngabe imibuzo enjani? Futhi wena uyiphendula kanjani?
 - b. Uma kungu cha, ngabe uyitshelani ingane ngalemithi?

Ukudlulisa ukuphathwa kwemithi

32. Uchanga ukuthi umntwana wakho uzokwazi nini ukuzinakekela ngokuthatha imithi na?
33. Ngabe uzosikhetha kanjani isikhathi okuyisona-sona?
34. Ngabe yini ozoyifundisa umntwana wakho uma eseqala ukuzithathela yena imithi?
35. Ngabe uzoba nasiqiniseko siphik ukuthi umntwana uwidla ngendlela eyiyo imithi?

Okuvamile kanye nokuvala

36. Ngabe kukhona ofuna ukungibuza kona ngale mithi edliwa umntwana wakho, noma okunye ongathanda ukungitshela kona mayelana nemithi kanye nokunikezele imithi umntwana wakho?

Appendix D

Interview schedule – Child

Introduction and opening

1. Discussion about nature of research and obtaining child assent
2. You can call me Aunty Trish.
3. Are you having a good day today?

Practical aspects

4. What time did you have to leave your house to come here?
5. Who did you come with to the clinic today? Can you draw a picture of you and this person coming to the clinic for me? (To be analyzed using Koppitz (1998) analysis system)
6. What did you come to the clinic for?
7. Do you like coming to the clinic?
8. How often do you have to come here?

Medication related knowledge

9. Can you tell me what medicine you take and when you take it?
10. Did you have your medicine today?
11. When do you take your medicine normally?
12. What does the medicine look and taste like?

Remembering medication

13. Do you sometimes skip your medicine or forget your medicine?
 - a. If yes, how often do you forget it?
 - b. If no, who/what helps you to remember to take it?
14. Do you usually remember to take your medicine on your own or do you need help?

Medication related experiences

15. What do you like about the medicine?
16. What don't you like about the medicine?
17. Can you draw me a picture about how the medicine makes you feel? (Provide a body outline – gingerbread man style)
18. Tell me about this picture.(To be analyzed using interpretive techniques)
19. Is there anything about the medicine that makes you sad, or that makes you not feel nice?
20. Is there anything about the medicine that makes you happy, or that does make you feel nice?

Medication action and purpose

21. What do you think the medicine is doing to your body?
22. Can you draw me another picture, this one of what you think the medicine does to your body? (Provide a body outline – gingerbread man style)
23. Now, can you tell me about your picture – what are all the things you have drawn?

Social support

24. Is there anyone else you know who takes medicine daily? Are they on the same medicines as you or different medicine?

25. If yes, do they help you to remember your medicine?
26. If no, how does it make you feel that you are the only one who takes medicine?
27. Do any of your friends know about your medicine?
28. What do they think or say about your medicine?

Medication fatigue

29. Do you sometimes get tired of taking your medicine?
 - a. If yes, what makes you tired of taking it?
 - b. If no, how do you stay happy about it and make it fun?

General and closing

30. Is there anything else that you want to ask me, or tell me about your medicine?
31. Can you please draw me a last picture of you doing something that you enjoy?

Appendix E

Interview schedule – Child (isiZulu)

Isingeniso kanye nokuvula

1. izingxoxo mayelana nocwaningo lwemvelo kanye nokuthola imvume yomntwana.
2. Ungangibiza ngo Anti Trish.
3. Ngabe unosuku oluhle namuhla?

Izimo esibhekana nazo

4. Ngabe isiphi isikhathi obekumele usuke ngaso ekhaya uza lapha?
5. Ngabe ifike nobani lapha emitholampilo? Ungangi dwebela isithombe sakho kanye nesalo ofike naye niza lapha emtholampilo? (Ukuhlaziya usebenzisa i Koppitz (1998) indlela yehlaziyo)
6. Ngabe uzokwenzani lapha emitholampilo?
7. Ngabe uyathanda ukuvakashela lapha emitholampilo?
8. Ngabe uza kangakhi lapha emitholampilo?

Ulwazi olumayelana nemithi

9. Ungatshela ukuthi imiphi imithi oyidlayo nokuthi uyidla nini?
10. Ngabe uyidlile imithi yakho namuhla?
11. Uyithatha nini imithi yakho ngoku-jwayelekile?
12. Ngabe imithi ibukeka kanjani futhi inambitheka kanjani?

Ukukhumbula imithi

13. Ngabe kwezinye izikhathi uyeqisa isikhathi noma ukhohlwe ukudla imithi yakho?
 - a. Uma kungu yebo, kukangaki ukhohlwa ukudla imithi?
 - b. Uma kungu cha, Ubani/ yini ekusiza ukuthi ukhumbule ukudla imithi?
14. Ngabe ujwayele ukuzikhumbulela ukuthi kumele udle imithi noma udinga usizo?

Ulwazi olumayelana nemithi

15. Ngabe yini oyithandayo ngale mithi?
16. Ngabe yini ongayithandi ngale mithi?
17. Ungangi dwebela isithombe ukukhombisa ukuthi ikwenza uzizwe unjani lemithi? (munikeze into engumfanekiso womzimba – njenge Gingerbread man)
18. Ake ungixoxele ngalesi sithombe. (Ukuhlaziya usebenzisa isu lokuhumusha).
19. Ngabe kukhona okukuphatha kabi ngale mithi noma okwenza ungazizwa uphatheke kahle?
20. Ngabe kukhona okukuphatha kahle ngale mithi noma okwenza uzizwe uphatheke kahle?

Inhlososo kanye nokusebenza kwemithi

21. Uchabanga ukuthi imithi yenza muphi umsebenzi emzimbeni wakho?
22. Ungangidwebela esinye isithombe, lesi kube esikhombisa ukuthi ucabanga ukuthi imithi yenzani emzimbeni wakho (munikeze into engumfanekiso womzimba – njenge Gingerbread man)
23. Manje, ungangixoxela ngalesi sithombe – ngabe ziyini zonke lezi zinto ozidwebile?

Ukesekwa ngabanye abantu

24. Ngabe ukhona omunye omaziyo odla imithi nsuku zonke? Ngabe badla imithi efanayo nalena oyidla wena noma imithi eyehlukile?
25. Uma kunguyebo, ngabe bayakusiza ukuthi ukhumbule ukudla eyakho imithi?
26. Uma kungu cha, Ngabe kukuphatha kanjani ukuthi nguweni kuphela othatha imithi?
27. Ngabe abangani bakho bayazi ukuthi kukhona imithi oyidlayo?
28. Ngabe bacabangani noma bathini ngemithi yakho?

Ukukhathala imithi

29. Ngabe kwezinye izikhathi uyakhathala ukudla imithi?
 - a. Uma kungu yebo, ngabe yini eyenza ukhathale ukudla imithi?
 - b. Uma kungu cha, Uhlala kanjani uthokozile ngemithi yakho futhi wenza kube umdlalo?

Okuvamile kanye nokuvala

30. Ngabe kukhona ofuna ukungibuza kona noma ukungitshela nge mithi yakho?
31. Ungangidwebele isithombe sokugcina sakho lapho wenza khona into ojabulelayo ukuyenza?

Appendix F

Consent for adult and child participation – English

School of Psychology

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South Africa



To whom it may concern,

Factors influencing compliance in taking ARV treatment in children between 8 and 12 years of age

I am asking for your consent for both you and your child to participate in my research project. I will be conducting a research project towards my Masters Degree in Counselling Psychology at the University of KwaZulu-Natal. The project aims to assess what factors contribute to compliance, or lack thereof, in taking ARV's in children between the ages of 8 and 12 years. Your child has been identified by medical staff in the clinic as someone who meets the criteria of the study as laid out by the researchers. These criteria include, amongst other things, age, and that they are on ARV treatment.

Involvement in the project will require that you participate in two 45 minute interviews with me as the researcher. The interviews will take the form of me asking you questions about medication and the way in which you and your child deal with taking the medication prescribed at this clinic. I will tape record the interviews and will later transcribe them so that I have an accurate record of your responses. The first interview will occur today if possible and the second interview at your next clinic visit. If today is not convenient for you, we can arrange an alternate day.

I would also like to interview your child. Your child's involvement in the project will require that he/she participate in a 45 minute interview with me. The interview will take the form of some questions posed to the child by myself, as well as some time allocated for play and drawing of pictures which are concerned with the child's understanding of the medication that they take and how it makes them feel. The findings of the interview will be recorded in writing and on tape, as well as photographs being taken of the pictures drawn, to examine at a later time. At no time will any photographs be taken of your child. Questions will revolve solely around the child's understanding and perception of their medication. At no point will the child's HIV positive status be disclosed to them if they are not already aware of it.

There will be no remuneration in cash or kind for participation in the project but it would be a privilege for me to participate with each individual. The identities of all participants, including yours, will be kept

confidential and no identifying information will be included in the completed research reports. You may withdraw at any time and are under no obligation to participate in any discussion or answer any question which you object to. You will experience no adverse effects from such withdrawal or refusal. Any concerns or questions are welcome and I will be of assistance whenever and wherever possible.

Sincerely,

Trish Phipson
Counselling Psychology Masters Student

Bev Killian (PhD)
Supervisor
Head: Child and Family Centre

I..... (Full name of caregiver) hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to participating in the research project. I also grant you permission to interview my child (Child's full name)..... (date of birth) whom I have brought to the clinic. I understand that the interviews will be tape recorded, and that I, and/or the child, am at liberty to withdraw from the project at any time should I/they so desire.

SIGNATURE

DATE

.....

.....

Appendix G

Consent for adult and child participation – isiZulu

School of Psychology
P/Bag X01 Scottsville
PIETERMARITZBURG, 3209
South Africa



Sawubona,

Ukuhlanganyele isifundweni sokusesetshenziswa kwemshanguzo ama-ARV kubantwana abanemiyaka esukela ku 8 kuya kwengu 12

Ngiyacela imvumo yakho ekememeni wena nomtwana wakho kucubungulo esizobe silwenza. Ngizobe ngenza lolungubungulo mayelana nengxenye yesifundo zami ze Psychology e University yakwa Zulu Natal. Lolucubungulo lumayelana nokulandelela kahle ukuthi lemishanguzo ama-ARV ukuthi izingane eziphakathi kewmiyaka engo 8 kuya kwengu 12 ziyisebenzisa kanjani. Ingane yakho ikhethiwe unompilo umtholampilo wangakini ukuze senze naye lolucubungulo. Ukhethwe ngenxa yeminyaka yakhe nanokuthi uyayisebenzisa lemishanguzo ama-ARV.

Ukuze ukwazi ukuthi ube ingxenye yaloludaba kumele ukwazi ukuhlanganyela nami kabili, umhlangano uwodwa uzothatha imizuzu engu 45. Kulomhlangano ngizobe ngibuza imibuzo ngalemishanguzo nanokuthi wena nomtwana wakho nibhekana kanjani nokuphuza limithi enisuke niyiniwe ekliniki. Inkulamo yethu ngizobe sengiyiqopha kwi tape recorder ukuze uma sesiqedile sikwazi ukuthi sobabili siyilalele ukuzwe uzwe ukuthi uphendule kanjani nokuthi uyavumelana yini nalokhu okuqoshiwe. Umhlangano wethu wokuqala ungaba namhlanje uma ungakwazi, kodwa uma ungeke ukwazi singahlela olunye usuku wena ongakwazi ukuthi sihlangane ngalo.

Ngizothanda futhi ukuba ngihlangane nomtwana wakho ukuze ngikwazi naye ukumbuzisa imibuzo, naye ke kuzomele akwazi ukuchitha isikhathi isiyimizuzu engu 45 nami izigaba ezimbili. Lomhlangano ke wona ngizobe ngibuza umntwana wakho imibuzo siphinde sibe futhi nesikhathi lapho sizobe khona sizidwebela izithombe ezimayelana nokuthi umntwana wakho okuphi ekuqondayo nemicabango yayo ngalemishanguzo, nonokuthi kuyenza azwizwe kanjani ngayo. Nawo ke lomhlangano uzoqoshwa nge tape recorder uphindwe ubhalwe naphansi. Zizoshutha nezithombe zemidwebo ezobe idwesthwe izingane ukuze sikwazi ukuthi sibuye sizibheke ekuhambeni kwesikhathi. Siyathembisa futhi ukuthi izingane zona angeke sishuthwe izithombe. Imibuzo

esizoyibuza umntwana wakho imibuzo elingana nenqondo yayo nanokuthi yona icabangani ngalemithi. Isinalo ilungelo lokuthi sisthele ingane ngemiphumela yayo yesandulela ngculaza (HIV) uma kuwukuthi wena mzali wayo awukaze uyisthele.

Akukho mali ezutholwa ngokuhlanganyela kulemhlango, kodwa kuzonika mina ithuba lokuthi ngikwazi ukuhlanganyela nawe ekuxoxeni ngalemishanguzo ngizwe novo lwakho. Lokuhlangana kozogcinwa kwiyimfihlo phakathi kwethu, akekho omunye umuntu ozokwazi ngakho, futhi angeke sithathe umazisi wakho. Kulomhlango umuntu unelungelo lokuhoxisa uma engasathandi ukubuzwa imibuzo, futhi awuphoqiwe ukuphendula imibuzo ongathandi ukuyiphendula. Uma kukhona ongakuqondi kahle, unelungelo lokuthi ungibuze, nami ngizozama ukuphendula yonke imibuzo yakho.

Ozithobayo,

Trish Phipson

Bev Killian (PhD)

Mina.....(amagama aphelele asonhlala kahle) ngiyavuma ukuthi ngiyayiqonda imibandelo yalelifomi namayelani nalolucubungulo. Ngiyavuma ukuthi ngihlanganye nani kulemihlangano. Futhi ngiyininika nemvumo yokuthi nihlangane nengane yami niyibuze imibuzo

.....(amagama engane aphelele).....(usuku lokuzalwa) lo engimlethe lapha ekliniki. Ngiyaqonda futhi ukuthi lomhlango izoqoshwa nge tape recorder, nokuthi mina nengane yami sinelungelo lokuthi singahoxisa kulomhlango nomanini uma sithanda.

SAYINA

USUKU

.....

.....

Appendix H

Non-disclosure agreement

Factors influencing ARV compliance in a small group of children between 8 and 12 years of age

I.....consent to assisting in the research project named above. In accordance with the ethical guidelines governing this research, I understand that the confidentiality of all clients and participants affected by the study must be protected at all times. I hereby agree to maintain the anonymity of all participants and I contract myself to not disclose any information to any party outside of the research team. Information will only be disclosed to the research team with the consent of the client.

Signed:

Capacity:

Date:

Appendix I

Non-recording of clients' participation or lack thereof

Factors influencing ARV compliance in a small group of children between 8 and 12 years of age

I.....agree that there will be no recording of the clients' participation, or lack thereof in their patient file. There will be no documentation of their agreement or refusal at any point in time

Signed:

Capacity:

Date:

Appendix J

HDSS Ethical clearance



Dear Trish Phipson

Re: ETHICAL CLEARANCE

The Higher degrees committee of the School of psychology met and considered your research proposal and request for ethical clearance. The committee gives you permission to proceed with your research project. This permission is subject to review by the faculty ethics board. You should receive a letter from the Faculty Higher degrees Committee within one month of this letter confirming your ethical permission to continue with your research.

Yours sincerely

A handwritten signature in black ink, appearing to read "Lance Lachenicht".

Lance Lachenicht, PhD
Pp Higher degrees committee
School of Psychology
UKZN

23 April 2010

School of Psychology

Postal Address: Private Bag X01, Scottsville, Pietermaritzburg 3209, South Africa

Telephone: +27 (0)33 260 5853

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Email: grantham@ukzn.ac.za

Website: www.ukzn.ac.za

Founding Campuses:

Edgewood

Howard College

Medical School

Pietermaritzburg

Westville

Appendix K

Department of Health Ethical Clearance



Health Research & Knowledge Management sub-component
10 – 102 Natalia Building, 330 Langalibalele Street
Private Bag x9051
Pietermaritzburg
3200
Tel.: 033 – 395 2805
Fax.: 033 – 394 3782
Email.: hrkm@kznhealth.gov.za
www.kznhealth.gov.za

Reference: HRKM087-10
Enquiries: Mr X. Xaba
Telephone: 033-395 2805

10 June 2010


Dear Ms T. Phipson

Subject: Approval of Research

1. The research proposal titled “**Factors influencing compliance in taking ARV treatment in a small group of children between 8 and 12 years**” was reviewed by the KwaZulu-Natal Department of Health. The proposal is hereby **approved** for research to be undertaken at the Edendale Hospital.
2. You are requested to undertake the following:
 - a. Make the necessary arrangement with identified facility before commencing with your research project.
 - b. Provide an interim progress reports and final report (electronic and hard copies) when your research is complete.
3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za.

For any additional information please contact Mr X. Xaba on 033-395 2805.

Yours Sincerely


Dr. S.S.S. Buthelezi
Date: 18/6/2010
Chairperson: Provincial Health Research Committee
KwaZulu-Natal Department of Health

uMnyango Wezempilo . Departement van Gesondheid

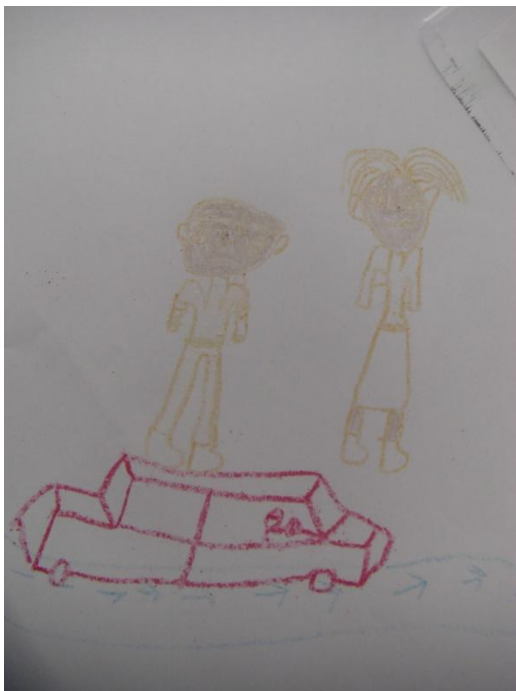
Fighting Disease, Fighting Poverty, Giving Hope

Appendix L

Child drawings



Dyad 1



Dyad 2



Dyad 3



Dyad 4



Dyad 5



Dyad 8