FACTORS AFFECTING ADHERENCE TO ANTI-RETROVIRAL THERAPY AMONG ADOLESCENTS (IN OR OUT OF SCHOOL) ATTENDING NSAMBYA HOME CARE AND TASO MULAGO HEALTH FACILITIES

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BY

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DECLARATION

I **KANGAVE ESTHER,** declare that this dissertation has not been submitted for any award in any University. All work is original unless otherwise acknowledged.

Signed: …… ……. Date: ……

APPROVAL

This work has been generated under my guidance and is now ready for submission to the exams council.

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Supervisor

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ACRONYMS AND ABBREVIATIONS

ARV	Antiretroviral therapy
HAART	Highly Active Antiretroviral therapy
MOH	Ministry of Health
REACH	Reaching Excellence in Adolescent Care & Health
TASO	The Aids Support Organisation
UNICEF	United Nations Children Fund
WHO	World Health Organisation

OPERATIONAL DEFINITIONS

Adherence to medication: Defined as taking at least 95% or more of the medication (ARV) as prescribed by the health care provider in a given period of time.

Adolescent: Defined as a boy/girl between the ages of 10 – 19 years (UNICEF, WHO, 1998).

Non adherence to medication: Defined as failure to take/missing to take at least <95% or less of the medication (ARV) as prescribed by the health care provider in a given period of time.

Opportunistic infection: Defined as infection for which incidence or and severity is raised in HIV related immune suppression.

Pill count: Defined as the number of pills ascertained by counting at a given moment in time.

Pill burden: Defined as the number of medication in a tablet formulation taken each day.

Self-report: Defined as an account on the drug's intake forwarded to the investigator by the client/care giver.

Side effects: Defined as the symptoms thought as having resulted from taking ARV during the period of treatment.

Unannounced pill: Defined as pill counts done at an impromptu.

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ABSTRACT

Objective

Whereas free ARVs are accessible to majority of HIV infected patients; adherence to ART is still a major challenge in public health especially among adolescents. Poor adherence can lead to increased viral load, reduced CD4 counts, resistance to drugs; which eventually lead to increased morbidity and mortality among adolescents. The study aimed at evaluating the factors influencing adherence to anti-retroviral therapy among HIV and AIDS infected adolescents.

Methodology

The cross- who were on ART at Nsambya Home Care and the Aids Support Organisation (TASO). adolescents between 10-19 years completed a self-administered questionnaire with open and close-ended questions. Key informant interviews for healthcare providers and caregivers were conducted to assess individual factors, health care facility related

factors; drug-related factors; and school /home related factors affecting adherence among in or out of school adolescents. Data was presented using graphs and frequency tables. Data was analysed using SPSS (version 11.5).

Results

Out of 173 participants, 136 completed the questionnaire. Forty-seven percent of adolescents who were in school; and forty six percent of adolescents who were out of school adhered (≥95% adherence). Among these were 59 (56.7%) adolescents from Nsambya and 25 (43.3%) from Taso. About 35 (35%) adolescents who were in school and 6 (25%) adolescents out of school adhered using the one week self report measure. The one day self-report revealed that 84 (80.8%) adolescents in school and 13 (54.2%) out of school adolescents adhered to ART. Only 48 (48.5%) adolescents in school and 11 (47.8%) adolescents out of school adhered to ART on a 5 day self report. On the other hand, the pill count measure showed that all adolescents attained ≤95% adherence (sub-optimal) with majority taking between 80-94% of their medication during the period under review.

The factors which were significantly associated with adherence to ART among adolescents in schools were; distance one lives away from the health centre ($\chi 2 = 4.266$, df = 1, p= 0.039< 0.05), religion ($X^2 = 22$, df, = 12, p = 0.034), alcohol consumption ($X^2 = 6$, df = 2, P =.048); and the maximum time one can wait at the health centre ($X^2 = 9.52$, df = 4, P =.049).

The following factors influenced adherence among school going adolescents though they did not have statistical significance.

Peer support clubs; privacy; non-disclosure; lack of water for swallowing drugs; school schedules and pill burden.

Adherence among adadolescents who were out of school was greatly influenced by the transport to clinic; poor diet; stigma and lifestyle

Both groups were equally affected by reaction to drugs; forgetfulness; duration on ART and type of drug; and poor counselling services by healthcare service providers. Key informants revealed that transport to clinics for pill re-fills; denial of permission, attitude

of healthcare service providers and stigma affected adherence to ART negatively among both groups.

CHAPTER ONE

INTRODUCTION AND BACKGROUND

1.1 Introduction

This chapter includs the back ground to the study, statement of the problem, general and specific objectives, research questions, significance of the study, conceptual framework, and the operational definitions of the concepts in the study.

The study is about Factors affecting adherence to anti-retroviral therapy among adolescents (in or out of school) attending Nsambya home care and TASO mulago health facilities.

1.2 Back ground

The study was carried out in Nsambya Home Care and TASO Mulago

The Dependent variable was adherence to ART, taking more than or equal to 95 percent of the ARV as per operational definition was assigned adherent while less than 95 percent non-adherent in this study.

Some of the Independent Variables were Clients' socio demographic characteristics expressed as participants' age, sex, and religion, level of education, occupation, in or out of school, and ease of obtaining permission to come and refill ARV, distance from the health facility, number of meals, support from school or not and class was collected from study subjects.

By the end of 2009, more than 33 million people were living with HIV worldwide, with about half of new infections among those under age 25 years. Young people, of ages 15-24 years, account for 41% of new HIV infections (UNAIDS, 2010)

World Health Organisation (WHO) defines adolescents as individuals aged 10–19 years and the youth as those aged 10–24 years. Adolescence is the transition between childhood and adulthood. Adolescence is characterized by major physical, emotional and cognitive

changes as well as significant changes in the relationship between the adolescent and their family and peers.

These changes and lifestyle may lead to non-adherence to medications in their efforts to discover more yet with Human Immune Virus (HIV) infection, one of the foremost concerns is the ability of people living with HIV/AIDS to maintain near perfect adherence to ART over a long time.

Lack of adherence to ART is one of the main causes for failure of the treatment worldwide and one of the main concerns when providing ART to developing countries. There is evidence that 95% or more of adherence to ART are associated with better virological and immunological outcomes (Paterson et al, 2003).

For instance, a study in US of 120 adolescents found that only 24% of them reached and maintained undetectable viral loads (UVLs). Murphy, Sarr & Durako *et al.,* (2003) reported that 28% of adolescents their study were adherent to ART; while Belzer *et al*, (1999) found about 61% HIV adolescents were adherent to ART. A cohort study by Nachega, Hislop, Nguyen, Dowdy, Chaisson *et al.,* (2009) revealed that adolescents are more likely to have low levels of virological suppression and adherence than adults.

Whereas high levels of ART adherence are significant for suppressing the HIV virus and reducing morbidity and death among HIV infected children, adherence to ART has become a major public health concern for many countries. Many scholars argue that, attaining 95% or more of adherence to ART results into better virological and immunological outcomes for HIV patients. Conversely, no consensus has been reached concerning the level of ART adherence required to achieve optimal virologic response (UNAIDS Report, 2008).

Developed in research have shown that while adherence rates of greater than 95% were usually considered to be compulsory for adequate response to non-boosted protease inhibitor-based ART regimens (Paterson *et al*, 2000); on the contrary, Non-Nucleoside Reverse Transcriptase Inhibitor (NNRTI)-based ART often leads to viral suppression at moderate levels of adherence (70%–90%). However, individuals with such "moderate" adherence levels are likely to have improved outcomes with higher adherence (http://www.ncbi.nlm.nih.gov/pubmed).

Adherence to medication (or compliance with medication), is the extent to which patients are supposed to follow medical instructions. It is recommended that HIV patients achieve at least 95% adherence to HAART in order to suppress viral replication and resistance (Rudy et al, 2008). Medical adherence is also defined as a complex behaviour that influences the extent to which an individual takes medication as prescribed (Bakeera-Kitaka, 2006).

A pilot survey of 31 youth (ages 13–24 years) from a multidisciplinary adolescent HIV clinic reported that 61% of the subjects self-reported >90% compliance with their medications in the previous 90 days (Belzer *et al*, 1999).

Nsambya hospital is a faith based hospital located in the suburbs of Kampala, Uganda. In 1987, Nsambya Home Care (NHC) department was introduced to provide Aids patient care. Initially, NHC had registered 327 clients of all age groups but the numbers have increased over the years. Currently, Nsambya Home Care provides ART to about 2000 clients of whom 198 are adolescents. NHC has outreach clinics that provide Behavioural change programs, Paediatric counselling, Income generating activities, Youth forum and

Pastoral care services among others. The Hospital was chosen because of the large number of adolescents and services rendered to clients.

The AIDS Support Organization (TASO) was founded in 1987 as an outpatient facility with its headquarters located in the suburbs of Kampala, Capital City of Uganda. There are 200 school-going adolescents registered at TASO, of whom 117, are on ART. TASO Mulago headquarters is located in the suburbs of Kampala in old Mulago hospital between ward seven and psychiatry ward. TASO is easy to access and the study subjects are easily available hence, making it suitable for the study.

Studies show that 50,000 out of 150,000 Ugandan children living with HIV require ARVs. However, only 14,000 (28%) are accessing treatment (Gross, 2004) moreover even among those on ART, adherence is still a challenge.

Many studies related to ART adherence have focused on adults as opposed to adolescents. One study by Rudy *et al*., (2005) revealed that adolescents have significant rates of non-adherence and face multiple personal barriers (Musiime et al, 2007). The findings from this study are expected to strengthen adherence among adolescents.

1.3 Statement of the Problem

At Nsambya Home Care 2000 adolescents are registered, of these 198 are on HAART (Annual report, 2010). Likewise in TASO Mulago health facility, there are about 1000 adolescents and at least 117 of these are on HAART (communicated by in charge of Adolescents on ART, TASO Mulago).

Statistics reveal that the average level of adherence in children on HAART in Sub-Saharan Africa (Nigeria) is between 74%-90% or 81.5%, while in Uganda, it is about 65.3% (Nabukeera, 2005).

In the past, Nsambya Home Care and TASO Mulago clinics have embraced MOH HIV policy guidelines of HIV counselling and testing, school based HIV/AIDS education and sensitising communities on benefits of consistent ARV therapy for HIV positive clients. Health care providers have been sensitised and trained on ARV treatment and how to ensure adherence. Despite the tremendous effort by the MOH, adolescents' attendances for ARV refills have been noted to be irregular and all these factors cut across other African countries like Nigeria and Kenya. Among the factors responsible for this would include side effects of ARV, pill burden, duration of treatment among others. The prevalence and factors influencing adherence to ART among HIV positive adolescents in Nsambya Home Care and TASO Mulago clinics are not known.

There is limited information on factors affecting adherence to ART among adolescents. To design effective interventions tailored to adolescents, it is important to assess factors affecting their adherence. The study aimed at assessing the factors affecting adherence among adolescents so as to make appropriate recommendations that would improve the situation across the country.

1.4 Justification of the Study

With the increasing number of new infections of HIV among respondents and the physiological and psychological changes from childhood to adulthood, adherence to ART is still a challenge. Adolescents in school may have an altered schedule for their ART dosing due to different activities. The situation may be worse for in boarding schools since they are away from home and barely supervised or reminded to take their drugs.

It is important to establish the socio-demographic and behavioural factors affecting adherence to ART among respondents in Nsambya home care and TASO in order to

design effective adherence strategies. Information generated from this study will be used by counsellors, clinicians and policy makers to facilitate the improvement and formulation of adherence to ART strategies for adolescent.

1.5 General Objective

The study assessed factors affecting adherence to ARV among HIV positive adolescents attending Nsambya Home Care and TASO Mulago during the period of six months to 24 months.

1.6 Specific Objectives

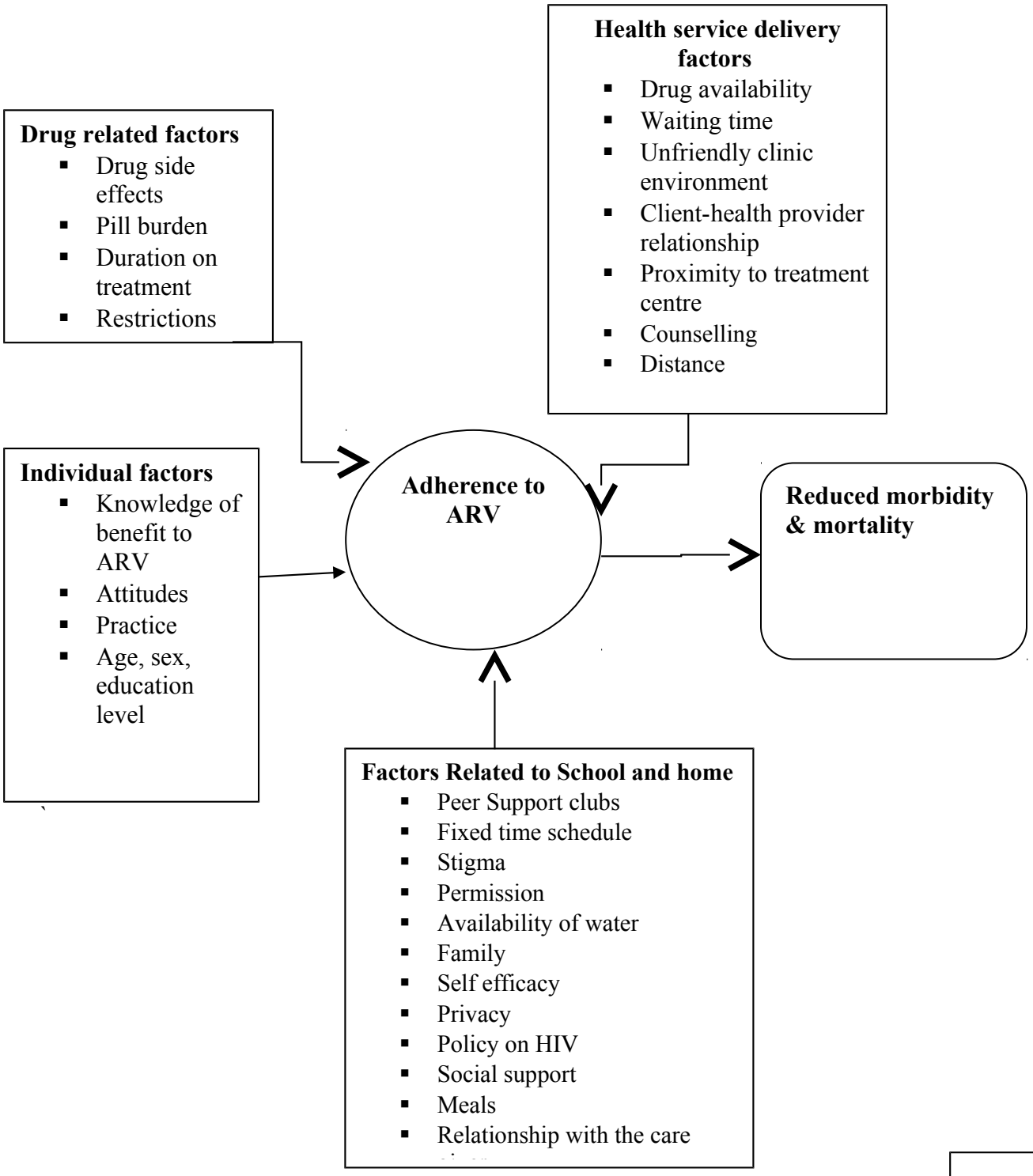
1. To establish adherence to ART among adolescents in school in proportion to adolescents out of school who were on ART at Nsambya Home Care and Taso Mulago health facilities.
2. To determine the factors associated with adherence to ART among adolescents who were in or out of school.
3. To investigate health facility based factors which may affect adherence to ART by the Adolescents
4. Discuss School /Home Related Factors Affecting Adherence to ART among Adolescents

1.7 Research Questions

1. What proportion of adolescents in or out of school who were on treatment at Nsambya Home Care and Taso Mulago health facilities adhered to ART?
2. What factors are associated with adherence among adolescents who were in or out of school?
3. Which health facility based factors affect adherence to ART among adolescents attending TASO (Mulago) and Nsambya Home Based care Health facility?

5. What are the School /Home Related Factors Affecting Adherence to ART among Adolescents

1.8 Conceptual framework of factors affecting adherence to antiretroviral therapy among adolescents in or out of school



The frame work above explains a combination of drug related factors, individual, health service delivery, factors related to school affect adherence levels of both school-going and non-school going adolescents who are on ART in Uganda.

If the above-named factors are favourable, they lead to high ART adherence levels (>95%), and consequently reduce morbidity and mortality among adolescent who are on ART.

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Adherence in Adolescents

The Standard Clinical definition of adherence is taking at least 95 percent of medications the right way, at the right time following a care plan, attending scheduled clinic appointments, picking up medicines on time and getting regular CD4 tests. Optimal adherence is an adherence rate of 95 percent or higher, a level generally deemed necessary for treatment success and to avoid development of resistance to treatment (Paterson *et al*., 2000); levels of adherence below 95 percent are sub-optimal.

A study by Rudy B; Murphy D; Harris D; Muenz L; and Ellen J., (2008) revealed that 62 percent out of 396 youth in the USA were adherent to HAART.

Whereas a comparative review of paediatric ART adherence studies of both poor and rich countries revealed that ART adherence levels (>75%) for adolescents in poor countries is higher than their counterparts from rich countries <75%); these percentages are sub-optimal (<95%).

The (Reaching Excellence in Adolescent Care & Health study found that only 41 percent of adolescents (12 -19 years) on ART reported more than 95 percent adherence. In the same cohort, Murphy *et al* (2003) reported that only 28.3 percent of adolescents reported taking all of their ART medicine in the previous month.

2.1.0 Factors Affecting Adherence

Factors affecting adherence fall into the following groups; patient factors like drug use, alcohol use, age, sex and ethnicity; medication regimen for example dosing complexity,

number of pills and food requirements; the patient-health-care provider relationship and the system of care.

2.1.1 Factors Related to the Health Care System

Several studies (Byakika, UNICEF, & SHAH 2009) found that factors related to healthcare systems affect adherence to ART either positively or negatively. Limited access to ARVs and health care facilities, poor counselling services, unfriendly clinical environment, lack of social-economic or psychological support were some of the factors cited in their study that affect adherence negatively among adolescents as well.

2.1.2 Location of Health Facility

In Uganda a large percentage of Paediatric HIV/AIDS treatment sites are located within the central region and major towns in national and regional referral hospitals, yet 88 percent of the population lives in rural areas (Annual Report, 2008).

Bagambe et al; 2008 reported that adolescents who live far from the health service facilities are less likely to return for ARV re-fills. It was further revealed that when patients, re-locate without leaving any trace or contacts, it becomes difficult for the health providers to follow them up, hence failure to adhere. Furthermore, it was found that 44 percent of children and adolescents at Mulago hospital were non-adherent and this was especially common among those who lived far away and/or were healthier. The difficulty of travelling for health services is compounded for adolescents, who depend on adult guardians; it is important for adolescents to ensure that they understand the importance of health care and the health care providers need to deliver health services and support as close to adolescents' home as possible.

A qualitative study by Sibhatu *et al*., (2009) in Ethiopia found that caregivers experienced problems like lack of transportation and economic problems in the households.

2.1.3 Poor Pharmacy Re-fill

A study conducted in Uganda by Bakanda, Birungi, Mwesigwa, Nachega, Chan *et al.,* (2011) among HIV-infected adolescents on ART cited poor pharmacy re-fill; and failure to follow-up patients who do not follow their scheduled appointments as one of the factors affecting adherence.

Type of Health Care Sector / programme

A study conducted in Southern Africa by Nachega *et al.,*(2009), revealed that adherence is determined by the type of sector /programme providing ART. Bakanda *et al.,* (2011), in their study at TASO – Uganda found that adolescents who received ART from private sector had higher levels of adherence than those under the public sector. This is because, HIV programmes under the private sector have established systems in place; and better funding that enhance adherence compared to the public sector.

2.2. Factors Related to the Patient's Families or Caregivers

HIV-infected adolescents experience special issues with adherence. For instance they may be dependent on adults for administration of their drugs, and this means that their adherence is only as good as that which their caregivers can achieve.

Establishing and maintaining adherence to medication is a difficult task for individuals with chronic illness, even when the treatment regimen is simple and the patient is clearly symptomatic (Brogly *et al.,* 2005).

The lifestyle of adolescents is influenced by treatment regimes which interfere with school or outdoor activities or even their vocations. Adherence to ART calls for conformity to strict schedules of multiple medications and frequent dosing, which have significant negative adverse effects. Rudy (2005) observed that adolescents living with HIV are faced with numerous challenges raging from depression, behavioural problems, illness of parents /guardians and cognitive deficit which interfere with adherence to HAART.

Patient adherence is known to improve viral suppression, slow progression to AIDS and is considered a cornerstone in preventing the development of antiretroviral resistance (Bangsberg *et al.,* (2004). It has been reported that outcome expectancy regarding antiretroviral treatment enhances adherence (Kleeberg & Rudy, 2007).

Murphy *et al.,* (2005) found that decreased adherence to ART regimens was associated with later HIV disease stage, more alcohol use, dropping out of high school, and lower CD4 count. The subjects included in the REACH study were infected as teens, primarily through sexual behaviour, and were old enough to be interviewed (mean age: 18.4 years; range: 15-22 years) and to report on their own medication adherence. Identifying children and adolescents who have assumed responsibility for medication administration, along with factors associated with taking on such responsibility, is important, because such knowledge helps target interventions for improving adherence.

Oftentimes, adolescents depend on caregivers /or family members to achieve optimal adherence. However, at times family members are also burdened with other factors such as illness, psychosocial factors, medication regimens and costs associated with medical treatment, which act as barriers to adherence (Steel & Chesney, 2004).

2.2.1 Education Level of Caregivers

It has been argued that for effective management of ART, caregivers need to understand and adhere to the instructions which, sometimes vary with changes in treatment prescribed for children. Poor adherence has been reported especially among children whose caregivers are uneducated and yet they happen to be the majority especially in sub-saharan Africa (Cupsa, Gheonea, Bulucea *et al.,* (2000) and Wrubel, Moskowitz, Richards *et al.,* (2005).

2.2.2 Responsibility for Adherence

Children living with HIV sometimes do experience retardation in development, which hinder their ability to adhere to ART thereby necessitating the help of caregivers. Nonetheless, if caregivers do not understand such challenges or where they fail to assess the capacity of their children to take medication, it results into poor adherence among adolescents (De Baets, Ramet, Msellati *et al.,* (2008).

2.2.3 Biological Relationship

Non-biologic caregivers are associated with negative adherence to ART while biologic caregivers enhance adherence due to emotional ties. Similarly, caregivers who are HIV positive tend to emphasise with their children thus leading to high adherence (Cupsa, Gheonea, Bulucea, *et al.,* 2000).

2.2.4 Permanence of Caregiver

It has been documented that where the primary caregiver moves away from the home, and leaves the adolescent under the care of different caregivers who may not be equipped

with ART adherence skills, the medication routine may be altered thus affecting adherence (Fassinou, Elenga, Rouet *et al.,* (2004).

2.2.5 Child-caregiver Relationship

Poor relationship between caregiver and patients has a negative impact on adherence. Failure by caregivers to share their anticipations with adolescents negatively affects ART adherence Wrubel *et al.*(2005).

2.2.6 Attitude of Caregivers

According to Hammami, Nostlinger, Hoerée *et al.,* (2004), ART adherence is determined by the attitude of the caregiver. They found that when the caregivers deny the sero-status of the adolescents, they will not be keen on administering the drugs thus, impacting negatively on ART adherence levels.

2.2.7 Orphans

adolescents who have lost either one or both parents have poor adherence because they end up being adopted by relatives or orphanages where they are stigmatised. Similarly, children who are raised by relatives especially in poverty stricken societies often face constraints of a**ccessing** treatment (re-fill) or lack of transport to health centres (Vreeman, Wiehe, Ayaya *et al.,* (2008).

2.2.8 Non-disclosure of HIV Status to Family Members

Although family members play a big role in helping children / adolescents adhere to ART, their caregivers are often faced with a dilemma of whether or not to disclose the sero-status of children to their siblings. The support of family members is known to help infected children overcome the burden of coping with taking ARVs and other related stressful factors (Brouwer, Lok, Wolffers, *et al.* (2000).

2.2.9 Psycho-social Function of Caregiver

Primary caregivers in resource constrained economies like Uganda are faced with several stressful factors arising from physical and emotional demands by dependents /children on ARVs, which, in turn cause psycho-social functioning and poor adherence to ART (Mellis, Brackis-Cott, Dolezal Iet al.; (2006).

2.3 Non-disclosure of HIV Status to School nurse and teachers

Adherence for children and adolescents with HIV may be affected by their families' desire for secrecy about the condition for example parents may send children to school without drugs to hide the child's HIV-status from the school.

adolescents find adherence especially self-conscious and do not want to be different from their peers. HIV positive adolescents who do not disclose their status to teachers, peers or school nurses, do not receive support thus, failing to adhere to HAART. While those who disclose their status receive compassion /sympathy, counselling or help with medication, thus promoting adherence (Obarel, 2006).

Some adolescents often deny their HIV status while others are afraid of taking drugs in the presence of peers due to stigmatization hence, failure of adherence to ART. (Ferris et al, 2005).

Stigma amongst school going adolescents also found to negatively affect adherence to HAART (Nabukeera et al, 2007). A similar study by Birungi (2009) reported that HIV positive adolescents who disclose their status to their peers, are called nasty names or teased at schools. For instance, adolescents who attend boarding schools lack privacy while taking drugs and as a result, many of them fail to adhere to HAART because they fear to be stigmatised (Musisi, 2007).

2.4 Support from Health Care Providers

Positive relationships with doctors and counsellors have proven to be very effective in improving adherence and general quality of life for adolescents living with HIV; for instance this support is described as making the adolescentsadolescents feel loved and worthy (Musisi, 2007).

Physician's communication of the importance of ART adherence is very vital (Sibhatu *et al*., 2009). Another study by Rueda, Park-Wyllie, Bayoumi *et al.,* (2006) established that patients who are educated by health-care workers on how to take ART have high levels of adherence than those who are not taught. Nyambura (2009) in her study on factors that influence non-adherence to ART in Kenya found a ssignificant positive relationship between ability to follow ARV treatment and adherence. She attributed this positive relationship to the information given by healthcare providers to HIV patients about following the course of treatment, side effects that could result from medications, what to do to ensure ART adherence, advantages of pre-test and post counseling and during treatment and role of privacy during consultation.

Needs assessment among a adolescents on ART in Kampala found that 92 percent of the adolescents interviewed desired a separate clinic from the paediatric or adult clinics (Bakeera-Kitaka, 2006). Clinical stage of the disease and changes in health status especially among adolescents were also found associated with adherence to ART (Kline, Malvin, Mellins, 2003).

2.4.1 Peer Support Groups

Adherence among adolescents can be increased by peer support groups; the authors suggest that this model is effective in part because of enhanced relationships among infected youth and concerned adults along with enhanced communication between

families and service providers (Lyon et al, 2003). For instance one study conducted in Uganda reported that 27 percent of 130 participants who had been identified as non-adherent had their adherence levels raised to more than 95 percent after joining peer support groups (Musiime, 2002).

2.5 Factors Related to Drug /Medication

The qualitative study in Ethiopia by Sibhatu et al., (2009) found that high dosages (heavy pill burden), patient dislike of taking the medicine and children spitting out the medicine as causes of poor adherence to ART. Caregivers also reported that the time of administration of the prescribed drugs was conflicting with their normal working hours.

adolescents in boarding schools may not have people to support and monitor them with adherence to regimens (Nabukeera et al, 2007). Another reason is that they are afraid of being seen taking their drugs by others and they do not have a private place in which to swallow the pills.

Adherence to ART may also be affected by the medication itself such as size of pills, storage requirements (some drugs require refrigeration for liquid formulations) and palatability among others. Similarly, Pharmakodynamic properties of the drugs such as need for daily administration and amount of liquid or pill burden also affect adherence to ART (Castro, 2005; Mills *et al*, 2006). This study found similar results of number of adolescents who take combination for example, NVP percentage

2.5.1 Drug Regimen on combined ART and Adherence

According to Grierson *et al.*, (2000), patients who are on combination Antiretroviral Therapy (ART), are highly susceptible to poor adherence. In the same study , patients who are on more than one type ARVs are less likely to adhere to ARV due to frequency

of dosing complexity of the regimen (Williams and Friedland, 1997; Nakiyemba *et al.*, 2005). Poor adherence to ART is also associated with side effects of the drugs like excessive smell and sweating, which may affect the lifestyle of adolescents (Rosina, Crisp & Steinbeck, 2003

2.5.2 Poor diet

Some regimens require multiple and complex dosing schedules that may cause food interactions and thence affect adherence levels especially among school-going adolescents who may not dictate over meal-time schedules or diets (Osterberg & Blaschke, 2005; Nabukeera, 2005). Whereas this is may seem so, some scholars have argued that children who receive nutritional support had low adherence levels (Brouwer, Lok, Wolffers *et al.* (2000).

A qualitative study in Ethiopia on barriers and facilitators to ARV medication adherence among HIV-infected paediatric patients found that nutritional problems were a common barrier to patient adherence to medication regimens because food security is a prerequisite for the initiation and continuation of the treatment (Sibhatu *et al*., 2009).

2.5.2 High Pill Burden

In focus group discussions, care givers expressed that 5 pills were simply too many for the children to take (Musisi, 2007).

2.5.3 Stigmatisation

Stigma amongst school going adolescents also negatively affects adherence to HAART (Nabukeera et al, 2007). A similar study (Birungi, 2009) reported that HIV positive adolescents who disclose their status to their friends, are called nasty names or teased at schools. For instance, adolescents who attend boarding schools lack privacy while taking

drugs and as a result, many of them fail to adhere to HAART because they fear to be stigmatised (Musisi, 2007). For deleting

2.5.4 Lack of Proper Mechanisms for Health Care in Schools

Most school nurses, senior teachers, and counselling & guidance teachers who are supposed to provide some kind of support at school to HIV positive adolescents lack appropriate training in HIV care and support and are unable to enhance adherence to HAART. Support groups /clubs or services in school play an instrumental role in enhancing adherence to HAART among HIV infected adolescents. Unfortunately, there are few schools which have such clubs (Birungi, 2009).

HAART can reduce, suppress HIV replication, reduce HIV-related morbidity and mortality, and improve the quality of life of HIV-infected children and adults. However, HIV infected adolescents still face a challenge of adherence to HAART due to multiple barriers ranging from factors related to the individual, healthcare system and caregivers, and school environment among others. For instance one study on 130 children conducted in Uganda reported that 27 percent who had been non-adherent, had their adherence levels raised to more than 95 percent after joining peer support groups (Musiime, 2002). This indicates that such groups are very effective,

HIV status still attracts stigma thus, adolescents find it difficult to adhere to the prescribed regimen, and yet the effectiveness of ART in treatment of HIV infection requires high levels of adherence by patients.

2.5.5 Education Level of Adolescents

Study findings by Abah et al., (2004); Stone, (2004) & Nakiyemba et al., (2005) showed that low levels of education have a negative impact on the patients' level of adherence. It

is believed that adolescents who attend school have a better perception than the non school going adolescents of the disease and the need for treatment more likely to understand and adhere to the strict instructions associated with ARVs.

2.5.6 Age of Adolescent

On the whole, research findings seem to agree that ART adherence levels tend to correspond with the age of the HIV patients (Mellins, Brackis-Cott, *et al*. (2004). It was further established that adherence drops with increasing age among HIV-infected children. HIV infected adolescents usually suffer from retarded development and cognitive deficits, which affect their ability to comprehend treatment (Havens & Mellins (2008) and Rutter, Bishop, Pine *et al;* (2008).

These findings were supported by Nyambura (2009) who conducted a study in Kenya on non-adherence and found that only 2 percent out of 300 patients' adherent to ART were below 19 years while majority (81 percent) of 300 patients' adherent ART to be between 30-39 years.

2.5.7 Treatment Fatigue and Denial

According to Castrol, (2005); Nakiyemba et al.; (2005) and Mills *et al.,* (2006); some adolescents fail to adhere to ARVs due to the technicalities of ARVs such as treatment fatigue. Others live in a state of denial, lack hope while others sometimes fail to follow or understand instructions.

2.5.8 Psychosocial Function

It has been documented that adolescents who suffer from psychological disorders such as depression and anxiety have low levels of ART adherence. When the mental health of

adolescents is poor, they are most likely to lose hope, deny infection or even refuse to take their medication (Mellins *et al;* 2006).

Smith & Schuchman (2005) observed that patients who spend prolonged periods of medication are likely to become depressed. Depression has been associated with loss of energy, cognitive deficiency, reduced concentration among other factors.

CHAPTER THREE

3.0 METHODOLOGY

3.1 Study area

The study was carried out at Nsambya Home Care (NHC) – a department of Nsambya Hospital; which provides ART to about 4000 clients of whom 198 are adolescents; and TASO Mulago which has 200 school-going adolescents of whom 117 are on ART.

3.2 Study Population

The study population comprised adolescents in or Out of School on HAART at Nsambya Home Care and TASO Mulago, aged 10-19 year and health workers offering services at these centres.

3.3 Study Design

The study used a cross-sectional study and employed both qualitative and quantitative data collection methods.

3.4 Selection criteria

3.4.1 Inclusion criteria

Eligible clients included;

- All adolescents (in or out of school) aged 10-19 attending a clinic at Nsambya home care or TASO Mulago facility.
- HIV sero positive adolescents who had been on ART for at least three months at the time of the survey.

3.4.1 Exclusion Criteria

- Those who were unable to understand the questions in the tool.

- Those who were mentally unstable for different reasons.
- Clients perceived by the research assistants as being too ill to respond to the data collection tool.

3.5.1 Sample Size Calculation

The sample size was calculated using the Kish and Leslie (1965) formula for prevalence surveys

$$K = \frac{Z^2 (P)(1-P)}{d^2} \qquad N = \frac{K}{(1+ (K/Pop)}$$

Where

N = required sample size

K = sample size from an infinite population

P = estimated proportion of children on HAART who adhere to treatment (50%)

d = Absolute errors between the estimated and the true value = 0.05(5%)

Z = The present point corresponding to 95% confidence interval = 1.96.

Pop = number of children on HAART (Nsambya = 198; TASO = 117 = 315)

$$K = \frac{1.96^2 \text{x } 0.5(0.5)}{0.05^2} = 384 \quad N = \frac{384}{1 + (384/315)} = 173$$

Therefore the total number respondents was 173, since the ratio of respondents in Nsambya to the respondents in TASO Mulago is 2:1, the same ratio was used to calculate the number respondents from each centre which was 115 respodents from Nsambya and 58 respodents from TASO Mulago

3.5.2 Qualitative Sample

Key informant interviews were conducted with all health workers offering services to respodents at Nsambya Home Care & TASO. The health workers included 2 pharmacists who issue ARVs; 2 Doctors who prescribe ARVs; 2 Nurses who count the pills; 2 Counsellors /social workers who counsel adolescentsadolescents on adherence and 4 care givers from each site who administer ARVs.

3.6 Sampling Procedure

The study adopted systematic sampling technique. The researcher sought permission to access print outs of existing patients' database from the administrators of the two selected study sites. Study participants who fitted the selection criteria were randomly selected from the database print outs with the assistance of health service providers from each study site. The selected participants were briefed about the purpose of the study and consent, by one health service provider and the principal researcher during the clinic visits. The parents or caregivers were requested to consent for their children below 18 years of age while adolescentsadolescents above 18 years of age offered consented on their own. After obtaining consent, then every second patient was selected, until the required number was obtained from each site. The subjects underwent an interview on a structured questionnaire until the desired sample size was obtained by the researcher and research assistants**.** Key informants were interviewed by the principal researcher following a key informant's guide to obtain qualitative data.

Sampling interval for Nsambya = $\frac{\text{population of adolescents on ARV`s (198)}}{\text{Number to be selected (115)}}$ =1.7 =2

Sampling interval for TASO = $\frac{\text{population of adolescents on ARV`s (117)}}{\text{Number to be selected (58)}}$ =2

Therefore every 2nd person was picked following random selection.

3.7. Study Variables

The following variables were considered:

3.7.1 Dependent variable

The dependent variable was adherence to ART, taking more than or equal to 95 percent of the ARV as per operational definition was assigned adherent while less than 95 percent non-adherent in this study.

3.7.2 Independent Variables

3.7.2.1 Individual characteristics

Clients' socio demographic characteristics expressed as participants' age, sex, and religion, level of education, occupation, in or out of school, and ease of obtaining permission to come and refill ARV, distance from the health facility, number of meals, support from school or not and class was collected from study subjects.

Participants' knowledge and attitudes about HIV/AIDS and individual habits such as alcohol consumption were measured.

3.7.2.2 Drug Related Factors

Side effects of ARVs reported by the respondents like nauseas, vomiting, fever, lack of appetite and general body weakness, history of adverse reactions. Pill burden of ARV, duration of treatment measured by the time the respondent has been on ARV program.

3.7.2.3 Health Service Factors

Among the factors which were considered during the study were; accessibility of the treatment centres measured by distance from respondents home, cost of travelling to and from clinic, affordability of transport cost, and time spent by client before being attended

to by a health care provider measured as waiting time, and adherence rates. Similarly, interaction of health care provider with patient measured time by time spent with health care provider and explanation given to client about HIV/AIDS and ART, as well as availability of ART at the treatment centre and affordability of ARV by the client measured by cost incurred to access and uses ARV, history of counselling on adherence, availability of ARV on demand.

3.8 Data Collection Techniques

Data was collected using quantitative and qualitative data collection methods. A semi-structured questionnaire was used to interview respondents while key informant guide was used to collect qualitative data. The questionnaire was designed in both Luganda and English for those who could not speak fluent English and caretakers who were not educated.

A pre –testing was carried out on 10 respondents from Kawempe Home Care to enable the researcher identify any questions that require further clarity.

3.9 Quality Control Measures

Research assistants were trained on data collection methods and on the use of data collection tools before data collection. Research assistants proficient in English and Luganda were selected and trained for two days. The research assistants were taken through simplified versions of topics related to this study (HIV/AIDS, ARV, questionnaire translations (English to Luganda) and administration). Other qualities considered were interviewing skills and correct recording of responses. The principal researcher interviewed key informants**.** Pretesting of tools was done and these were refined after wards to improve on their precision.

3.10 Data Management and Analysis

3.10.1 Data Management

Quantitative data variables were coded and edited before entry into computer. Data was entered into the computer using Statistical Package for Social Sciences (SPSS). Double entry was conducted to ensure correctness of the entered data backup. The data was cleaned and stored by the investigator in a CD.

Qualitative techniques

Data was collected and organized in major themes which were assigned codes in order to organize, find patterns and to interpret data. The raw data forms were kept securely by the investigator throughout the course of the study. Thematic analysis was used to analyze data generated from key informant interviews with health workers and observations about practices and health facilities.

3.10.2 Data Analysis

Quantitative data was analysed using Statistical Package for Social Package (SPSS v16.0).

Results of univariante analysis were presented in frequency tables, pie charts, and graphs. Bivariate analysis using two-sample tests was used to determine factors that significantly influence adherence to ART.

The strength of association was determined between dependent and independent variables using Chi-square test.

The one day self-reported adherence was summarised as a ratio of the doses that was reported to have been taken over the total number of doses that were supposed to be have been taken according to the prescription expressed as a percentage. Adherence on one

days` self report, five days, one week and clinic pill count. Level of adherence was evaluated from the four methods as those respondents who scored at least 95 percent on any method.

Quantitative data was grouped under major themes: socio demographic and other client related factors; health service factors; medicine related factors and sub themes generated. Qualitative data was analysed using thematic technique. Direct quotations by respondents were recorded for latter use when presenting study findings.

3.11 Ethical Considerations

Ethical approval was obtained from International Health Sciences University Research Committee and Nsambya Home Care and TASO Mulago centers. Written informed consent was obtained from all study participants.

All information is kept confidential and no publications of this study will bear names of the participants.

The data was analysed by the investigator in consultation with a statistician. For purposes of future reference, the data will remain protected on the personal micro computer after the study and will be deleted after 2 years.

CHAPTER FOUR

RESULTS

4.0 Introduction

This chapter presents results and analysis on factors which affect adherence to ART among respondents who are in or out of school. The chapter presents the background characteristics of respondents and also presents individual factors, health care facilitity factors, home / school factors; and drug related factors in order to establish whether or not these had an effect on adherence to HAART among respondents who were either in or out of school. 173 participated in this study

4.1 Social Demographic Characteristics

The background characteristics presented in the study include age, gender, school status, education level, religious affilliation, school se3ction and treatment center. Table 1 shows the percentage distribution of the respondents according to the background characteristics.

Table 1: Background characteristics of respondents (n =173)

Characteristic	Category	Percentage (%)
Treament Centre	Taso	37.5
	Nsambya	62.5
Age(years)	10-14	35.6
	15-19	64.4
Gender	Male	37.3
	Female	62.3
School status	In school	81.2
	Not in school	18.8
Education level	Primary	28.2
	Ordinary level	34.3
	Advanced level	23.6
	Tertiary level	13.6
Religious affiliation	Catholic	35.3
	Protestant	25.7
	Islam	16.2
	Others	27.8
School section(n=110)	Boarding	33.6
	Day	66.4

Source: Primary Data

Table 1 shows that majority (62.5%) of the study respondents were on ART at Nsambya while 37.5% were on ART at TASO. 64.4% of the respondents were between 15 - 19 years while 35.6% were between 10 - 14 years. The table also shows that 62.7% of the respondents were female while 37.3% were male. Majority (81.2%) participants were in school. Of those who were in school, majority (66.4%) were in day section and 33.6% were in boarding section. Table 1 also shows that majority (34.5%) of the respondents were in ordinary level; 28.2% were in primary level; 23.6% were in advanced level while 13.6% were in tertiary institutions. The dominant religion was Catholics with 35.3% of the respondents , 25.7% were Protestants, 22.8% were affiliated with other religious sects and 16.2% were Muslims.

4.2: Proportion of Adherent respondents in school to Out of School who were on ART

Table 1 shows that majority (81.2%) participants were in school while 18.8% were out of school. The study sought to ascertain the proportion of adherent adolescents in and out of school as illustrated in table 2

Table 2: Proportion of adherent respondents in or Out of School who were on ART at Nsambya Home Care and Taso Mulago Health Facilities

	In School		Out of School	
Variable	**Adherence (≥95%)**	**Non adherence (<95%)**	**Adherence (≥95%)**	**Non adherence (<95%)**
1 Day Self-Report	84 (80.8%)	20 (19.2%)	13(54.2%)	11 (45.8%)
5 Day Self-Report	48 (48.5%)	51 (51.5%)	11 (47.8%)	12 (52.2%)
1 Week Self-Report	35 (35%)	65 (65%)	6 (25%)	18 (75%)
Unannounced Pill Count		104 (100%)		24 (100%)

Source: Primary Data

Table 2 shows that majority of the respondents were adherent the day before the study was conducted for both those in school and out of school (80.8% and 54.2%

respectively). The increase in time of self report indicates a decline in the level of adherence among respondents both among those in school and those out of school. Table 2 also shows that none of the respondents adhered under Unannounced Pill Count. The researcher also investigated the impact of schooling on adherence to ART, the results of which are shown in table 3.

Table 3: Association between schooling and adherence among adolescents to ARVs

	Adherence		
	Adherence (≥95%)	**Non Adherence (<95%)**	Total
In school	52(47.2%)	58(52.3%)	110(100.0%)
Out of school	12(46.1%)	14(53.8%)	25(100.0%)
Total	64(47.0%)	72(53.0%)	136(100.0%)

Pearson Chi-Square = 0.001, df = 1, p = 0.973

The results show no significant relationship between adolescents who are in school or not and ones adherence to ARVs (Pearson Chi-Square = 0.001, df = 1, p = 0.973> 0.05). However, those in school adhered slightly more (47.2%) compared to those out of school (46.1%). The table also shows that there were more (53.0%) whose adherence was below 95%.

4.4 Factors affecting Adherence to ART among In or Out of School Adolescents

The study also investigated different factors affecting adherence to ART among adolescents. Among other factors included the effect of background characteristics on adherence as shown in table 4.

Table 4: Socio demographic Characteristics of and their level of adherence to ARVs

Variable		N(%)	Adherence (≥95%)	Non adherence (<95%)	χ^2	P value
Sex	Male	62(45.6)	23(37.9%)	39(62.1%)	0.009	0.923
	Female	74(54.4)	29(38.7%)	45(61.3%)		
Religion	Catholic	42(34.7)	19(45.7%)	23(54.3%)	3.398	0.334
	Protestant	30(24.8)	17(57.6%)	13(42.4%)		
	Muslims	20(16.5)	9(45.0%)	11(55.5%)		
	Others	29(24.0)	18(63.3%)	11(36.7%)		
Schooling	In school	110(80.9)	73(66.7%)	37(33.3%)	0.799	0.377
	Not In school	26(19.1)	14(53.8%)	12(46.2%)		
School section	Boarding	30(26.9)	15(50.0%)	15(50.0%)	0.108	0.742
	Day	80(73.1)	43(53.8%)	37(46.3%)		
Age	10-14	41(33.9)	19(46.7%)	22(53.3%)	0.054	0.816
	15-19	80(66.1)	39(48.8%)	41(51.2%)		
Education level	Primary	29(30.2)	14(48.3%)	15(51.7%)	0.567	0.904
	Ordinary	31(32.3)	16(51.4%)	15(48.6%)		
	Advanced	21(21.9)	10(47.8%)	11(52.2%)		
	Tertiary	15(15.6)	6(40.0%)	9(60.0%)		
Distance to health centre	≤5km	47(40.9)	28(60.4%)	19(39.6%)	4.266	0.039
	>5km	68(59.1)	28(41.3%)	40(58.7%)		
Alcohol consumption	Yes	89(82.4)	30(33.7%)	59(66.3%)	0.799	0.377
	No	19(17.6)	9(48.6%)	10(51.4%)		

Source: Primary Data

Table 1 shows that there is no significant association between sex, religion, schooling, school section, age, education level and alcohol consumption with adherence to ARVs, at 0.05 level of significance. This is because all these variables have p values greater than 0.05. However, the table indicates that the level of adherence is relatively similar across sexes, that is, 37.9% for males and 38.7% for female.

The table also shows that adherence is highest among protestants (57.6%) compared to other religions. The table also indicates that respondents in school were more adherent

(66.7%) than 53.8% for those out of school. Adherence levels were better among day students (53.8%) than boarding students (50.0%). respondents who were between 15 and 19 years of age were more likely to adhere (48.8%) compared to the younger ones (46.7%). respondents in lower education levels like primary and ordinary level adhere more compared to tertiary and secondary levels of education. Adherence was higher among those who do not take alcohol (48.6%) compared to 33.7% who consume alcohol. There is a significant relationship between the distance one lives away from the health centre and level of adherence to ARVs ($\chi 2 = 4.266$, df = 1, p= 0.039< 0.05).Those who stay nearer to the health center have more adherence levels (60.4%) than those who stay far away from the health centre (41.3%). Table 5 further shows the effect of these factors on adherence considering those in school and those out of school.

Source: Primary Data

Table 3 shows that there is no significant relationship between variables like, age gender, and education level with levels of adherence among adolescents both in and out of school. This is because the generated p values are greater than the 0.05 level of significance. However, there is a significant relationship between religion and adherence only for respondents out of school ($X^2 = 22$, df, = 12, p = 0.034)

Other factors investigated include individual or personal behavioural factors such as life style (alcohol consumption) and drug related factors as illustrated in table 6 and table 7 respectively.

Table 5: Individual Factors Affecting Adherence to ART among In or Out of School Adolescents (n=136)

		In school		Out of school	
Variable	**Response**	**Adherence (≥95%)**	**Non Adherence (<95%)**	**Adherence (≥95%)**	**Non Adherence (<95%)**
Life style	Do not Consume alcohol	44	42	0	3
	Consume alcohol	2	2	8	7
	Sig. (0.05)	$X^2 = 9.5$, df = 4, P =.050		$X^2 = 6$, df = 2, P =.048	
Frequency of alcohol consumption	Every day	0	1	2	2
	< two times a week	1	3	0	2
	> two times a week	5	1	1	3
	Sig. (0.05)	$X^2 = 8.1$, df = 6, P =.227		$X^2 = 3.0$, df = 1, P=.083	
Amount of alcohol consumed	1 Bottle	5	1	1	1
	2 Bottles	1	2	2	2
	3 Bottles	0	1	0	3
	Sig. (0.05)	$X^2 = 5.2$, df = 3, P =.154		$X^2 = 5$, df = 4, P =.287	
Knowledge of the benefits of ART	Yes	41	45	9	8
	No	3	3	2	3
	Sig. (0.05)	$X^2 = 9.8$, df = 8, P =.278		$X^2 = 10.2$, df = 8, P =.248	
Reasons for taking the drug	To cure HIV/AIDS	1	3	0	1
	To suppress symptoms of HIV/AIDS	33	35	5	4
	Just for consolation	1	1	0	1
	Increases CD4 counts	10	6	5	4
	Sig. (0.05)	$X^2 = 5.6$, df = 12, P =.935		$X^2 = 17.1$, df = 16, P =.378	
Side effects of missing some doses	Yes	43	46	2	7

Source: Primary Data

Table 4 shows that of all the variables considered, lifestyle is the only variable which has a significant relationship with adherence among respondents both in school ($X^2 = 9.5$, df = 4, P =.050) and out of school ($X^2 = 6$, df = 2, P =.048). The life style considers whether one consumes alcohol or not.

Table 6 Drug-related Factors Affecting Adherence to ART Among In or Out of School Adolescents

		In school		Out of school	
Variable	**Response**	**Adherence (≥95%)**	**Non Adherence (<95%)**	**Adherence (≥95%)**	**Non Adherence (<95%)**
Duration on ART	6 months	3 (3.1%)	3 (3.1%)	0	1 (4.3%)
	7-12 months	4 (4.1%)	9 (5.2%)	4 (1.4%)	3 (13%)
	13-24 months	12 (12.4%)	22 (22.7%)	2 (8.7%)	2 (8.7%)
	24 months	29 (29.9%)	19 (19.6%)	5 (21.6%)	6 (26.1%)
	Sig. (0.05)	$X^2 = 11.6$, df = 12, P=.477		$X^2 = 11.8$, df = 12, P =.466	
Adverse reactionsto those drugs	Yes	30 (31.3%)	22 (22.9%)	6 (26.1%)	1 (4.3%)
	No	15 (15.6%)	29 (30.2%)	5 (21.7%)	2 (8.7%)
	Sig. (0.05)	$X^2 = 6.2$, df = 4, P=.183		$X^2 = 6.9$, df = 4, P=.137	
Type of drug	ARVS	29 (36.3%)	32 (40%)	7 (35%)	9 (45%)
	CBV & EFV	3 (3.8%)	5 (6.2%)	1 (5.0%)	1 (5.0%)
	NVP	2 (2.5%)	3 (3.5%)	1 (5.0%)	1 (5.0%)
	NVP & CBV	5 (6.3%)	1 (1.2%)	0	1 (5.0%)
	Sig. (0.05)	$X^2 = 6.9$, df = 12, P=865		$X^2 = 16.4$, df = 12, P=.174	

Source: Primary Data

Table 7: Other factors affecting adherence to ARVs among adolescents

Question	Response	Frequency	Percent
Have you missed taking ARVs at any time?	Yes	112	84.2
	No	21	15.8
	Total	133	100.0
If yes, number of times missed within 3 to 6 months	1 - 10	62	51.7
	11 - 20	43	35.8
	21 - 30	8	6.7
	31 - 40	4	3.3
	41 - 50	1	.8
	>50	2	1.7
	Total	112	100.0
Why did you miss taking your pill?	Forgot to take the pills	37	30.8
	Got side effects (skin rash /itching, nausea /vomiting etc)	53	44.2
	Perceived or actual lack of effect	1	.8
	Lack of transport	6	5.0
	I was instructed by the healthcare provider not to take	2	1.7
	Forgetfulness & Lack of transport	7	5.8
	Others (lack of food)	9	7.5
	Lack of access to dormitories	2	1.7
	lack of privacy	3	2.5
	Total	112	100.0
Does taking ARVs bother you in any way?	Yes	59	45.7
	No	70	54.3
	Total	129	100.0
If Yes, why?	Pill size	11	21.2
	side effects e.g. Vomiting & dizziness	15	28.8
	Stigma	8	15.4
	Pill burden	8	15.4
	Poor nutrition	4	7.7
	Got tired of taking drugs	5	9.6
	Time management	1	1.9
	Total	52	100.0

Source: Primary Data

The results indicate that adherence is highest among respondents who had been taking HAART for the last 24 months (29.9%). However, the duration one had been taking the drug has no significant effect on adherence among respondents both in and out of school. Results also show that those who have experienced any adverse reactions to drugs were more adherent (31.3%) than those who have not experienced any (15.6%). Adherence was highest among respondents who took ARVs (36.3%) compared to other drugs. However, the type of drug taken had no significant effect on adherence. ($X^2 = 6.9$, df = 12, P=865)

Other factors affecting adherence to ARVs among adolescents were investigated using questions whose responses are summarised in table 7.

Majority (84.2%) of the respondents had missed taking ARVs at one time. About 51.7% of those had missed pills between one to ten times. The major reason for missing the drugs was due to side effects (skin rash /itching, nausea /vomiting etc) with a percentage of 44.2; followed by forgetting as stated by 30.8 of the respondents. The table also indicates that the largest proportion of adolescents (54.3%) were not bothered by taking ARVs. Others attributed non-adherence to the side effects of taking ARVs such as vomiting & dizziness (28.8%), stigma (15.4%) and pill burden (15.4%) among others.

4.5 Facility Based Factors Affecting Adherence to ART among Adolescents

Factors related to the health facility included, the distance of the facility from the adolescents the time taken waiting for treatment at the treatment centre, privacy maintenance and quality of services offered at the health facility. Table 9 illustrates the effect of these factors on adherence.

Table 8: Health Facility Based Factors Affecting Adherence to ART among Adolescentsattending TASO (Mulago) and Nsambya Home Based Care Health Facility

		In school		Out of school	
Variable	**Response**	**Adherence (≥95%)**	**Non Adherence (<95%)**	**Adherence (≥95%)**	**Non Adherence (<95%)**
Waiting time	>30min	40 (40.4%)	40 (40.4%)	9 (39.1%)	11 (47.1%)
	≤30min	6 (8.1%)	11 (11.1%)	2 (8.7%)	1 (4.3%)

	Sig. (0.05)	$X^2 = 3.43$, df = 4, P =.488		$X^2 = 9.52$, df = 4, P =.049	
Privacy the health facility	Yes	39 (41.1%	44 (46.3%)	8 (34.8%)	8 (34.8%)
	No	7 (7.4%)	4 (5%)	3 (13%)	4 (17.4%)
	Sig. (0.05)	$X^2 = 2.8$, df = 4, P =.596		$X^2 = 3.6$, df = 4, P =.457	
Level of explanation	Good	30 (30.9%)	24 (24.8%)	7 (30.4%)	6 (26.1%)
	Fair	18 (18.6%)	23 (23.7%)	4 (17.4%)	4 (8.7%)
	Sig. (0.05)	$X^2 = 8.9$, df = 4, P =.353		$X^2 = 13.7$, df = 8, P =.091	
Pre-ART counselling	Yes	40 (40.8%)	48 (49%)	11 (47.8%)	8 (34.8%)
	No	8 (8.2%)	2 (2%)	0	4 (17.4%)
	Sig. (0.05)	X^2 =5.8, df = 4, P =.279		$X^2 = 7.9$, df = 4, P =.279	
Post-ART counselling	Yes	21 (21.6%)	10 (10.4%)	5 (21.7%)	0
	No	26 (26.8%)	40 (41.2%)	6 (26.1%)	12 (52.2%)
	Sig. (0.05)	X^2 =9.0, df = 4, P =.061		$X^2 = 6.8$, df = 4, P =.137	

Source: Primary Data

The level of adherence is greater among those who wait for more than 30 minutes to before seeing a doctor (40.4%); than 8.1% who can't wait for more than 30 minutes. There was a significant association ($X^2 = 9.52$, df = 4, P =.049) between waiting time and adherence to ART among adolescents who were out of school. Those who stated that there is privacy by the health workers were more adherent (41.1%) compared to those who doubted the privacy of their status among the health workers (7.4%). Adolescents who received good explanation from the health workers about the drugs than those who had not received any explanation at all. Adolescents who received counselling initially also adhered more than those who received none. However those who do not always get counselling adhered better than those who received counselling every time they visited the health centre. Results show no significant relationship between health facility based factors and adherence apart from waiting time among those who are not in school.

Table 9: School /Home Related Factors Affecting Adherence to ART among Adolescents attending TASO (Mulago) and Nsambya Home Based Care Health Facility

		In school		Out of school	
Variable	**Response**	**Adherence (≥95%)**	**Non Adherence (<95%)**	**Adherence (≥95%)**	**Non Adherence (<95%)**
School support	Yes	14 (14.6%)	4 (4.2%)		
	No	32 (33.3%)	56 (48%)		
	Sig. (0.05)	$X^2 = 8.3$, df = 4, P =.082			
Permission to go for drug re-fills	Always	28 (28.9%)	29 (29.9%)	4 (22.2%)	4 (22.2%)
	Sometimes	15 (15.5%)	14 (14.4%)	4 (22.2%)	3 (16.7%)
	Never	5 (5.2%)	6 (6.1%)	1 (5.6%)	2 (11.1%)
	Sig. (0.05)	$X^2 = 13$, df = 8, P =.108		$X^2 = 7.1$, df = 8, P =.524	
Availability of fresh water for swallowing your drugs	Always	20 (20.2%)	25 (25.5%)	8 (36.4%)	6 (27.2%)
	Sometimes	12 (12.1%)	9 (91.1%)	2 (9.1%)	4 (18.2%)
	In most cases no water	16 (16.2%	17 (17.11%)	0	2 (9.1%)
	Sig. (0.05)	$X^2 = 3.7$, df = 8, P =.880		$X^2 = 14.8$, df = 8, P =.062	
Number of meals per day	Once	0	2 (9.1%)	5 (5.2%)	5 (5.1%)
	Twice	7 (31.8%)	7 (31.8%)	27 (27.8%)	27 (27.8%)
	Three times a day	4 (18.2%	2 (9.1%)	14 (14.4%)	19 (19.6%)
	Sig. (0.05)	$X^2 = 5.76$, df =8, P =.674		$X^2 = 14.5$, df = 8, P =.177	

Source: Primary Data

The table shows that adherence is higher among those who receive no support from their schools (33.3%) than those who do not get school support (14.6%). The table also shows that those who are always or sometimes given permission to visit the health centre adhered more compared to those who are never permitted (5.2%). Adolescents who always access water for drinking adhered more (20.2%) compared to those who do not always get access to water. However, there was no significant relationship between home/school based factors (P>.005) and adherence to ART among adolescents who were either in or out of school.

4.5 A regression analysis of the factors affecting adherence to art among adolescents

A regression analysis was conducted to test the effect of some factors on the level of adherence such as age, number of meals, time taken on HAART, frequency of alcohol consumption and distance from the treatment centre. The level of adherence is measured as the number of days the respondent rightfully takes the prescribed drugs expressed as a percentage of the total number of days he is supposed to take the drugs in a particular period of time. The model is illustrated in tables 11 and 12 and 13.

Table 5: Regression Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.737[a]	.543	.238	.45594

Table 11 shows that the value of R^2 is 0.543 which shows that 54.3% of adherence is explained by the independent factors of age, number of meals, time taken on HAART, frequency of alcohol consumption and distance from the treatment centre.

Table 6: ANOVA

Model	Sum of Squares	df	Mean Square	F	Sig.
Regression	27.068	4	.370	1.780	.0071
Residual	175.709	6	.208		
Total	202.777	10			

Table 12 shows that the p value = 0.0071 a value which is less than the 0.05 level of significance. This implies that the overall model is statistically significant.

Table 7: Coefficients of the regression model

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	71.041	.553		1.881	0.063
Age	0.208	0.003	0.022	0.206	0.838
Average number of meals a week	1.923	0.047	0.290	0.968	0.021
Time taken on HAART	-0.358	0.284	0.462	1.260	0.047
Frequency of alcohol consumption	0.223	0.191	0.042	0.115	0.012
Distance from treatment site	0.369	0.407	0.286	0.907	0.009

Dependent Variable: adherence

The model shows that age and the constant are not statistically significant (table 13), while other variables are significant. The constant implies that with no effect from all the variables in the model, the adherence level is at 71%. A change in age by one year causes a change in adherence by 0.208 percent while a change in the number of meals per week by one causes an increase of adherence by 1.923 %. Time taken on HAART and frequency of alcohol consumption have a negative impact on the level of adherence while distance from the treatment site has a positive effect on the level of adherence in percentage.

CHAPTER FIVE

DISCUSSION OF FINDINGS

5.1 Introduction

This section presents a discussion of the findings in this study. Whereas most studies on ART adherence aim at establishing factors affecting adherence levels, this study explored factors that affect ART adherence among in or out of school adolescents. Adherence to medication in this study was defined as taking at least ninety-five percent or more of the medication (ARV) as prescribed by the health care provider in a given period of time. On the other hand, non adherence to medication was defined as failure to take or missing to take at least ninety-five percent or less of the medication (ARV) as prescribed by the health care provider in a given period of time.

5.1.1 Proportion of adolescents who were in or out of school and adhered to ART

On the whole, forty-four percent of adolescents in school compared to eight percent of adolescents out of school adhered to ART (≥95% adherence) using the one day self report, five day self report; and one week self report measures. These findings were lower than 96.4% level Nabukera et al (2005) found in their study. A significant relationship was established between adherence to ART and the school status among both in and out of school adolescents using the one day self report and the one week self report Nonetheless, no association between adherence and school status was revealed using the five-day self report. The unannounced pill count, considered to be the most objective measure showed that all adolescents (in and out of school) achieved sub-optimal adherence (≤95% adherence). The study discovered that 53 percent of the Adolescents achieved an average of less than 95 percent adherence. The findings of this study compare favourably with what Musiime et al, (2007) reported that adolescents have significant rates of non-adherence and face multiple personal barriers.

5.1.2 Factors Associated with Adherence among Adolescents

5.1.2.1 Individual Factors

Although no statistical association was found between age and adherence, high rates of adherence were reported by respodents aged between 15 to 19 years who were either in (25%) or out (5.8%) of school. This finding is supported by Abah *et al.* (2004); and Nyambura (2009) who found that adherence increased with increasing age.

There was no significant association between gender and adherence among adolescents who were in school nor those out of school . However, females in school (23%) adhered better than females who were out of school (6.6%). This finding was similar to that of Nyambura (2009) but was in contrast with findings of Abah *et al.* (2004).

The level of education had no significant association with adherence (By contrast, Nyambura (2009), found a strong association between adherence and education among adolescents in Kenya.

Some adolescents who were not in school had suspended taking drugs for several weeks before the study; others who were in school failed to adhere due to stigma and poor diet. This finding is consistentt with the findings of Ferris et al, (2005), Nabukeera et al. (2007); (Musisi, 2007); and Birungi (2009) who reported that adolescents who attend boarding schools failed to adhere to ART due to stigma.

Adolescents who were in day section adhered better than those who were in boarding section because most of them cited their parents as caregivers who constantly remind them to take their pills compared to their counterparts in boarding section who are stigmatised. This observation is in line to the observation of Nabukeera *et al.,*(2007) who found that boarding students had poor adherence to their drugs. This difference is because day students can easily access health centres outside the school and get monitoring by parents, school authorities and the general community, while boarding students are mainly monitored by the school authorities

All Adolescents who were in and out of school reported that ARVs alleviate the symptoms of HIV, improve one's health, and help to console oneself. However percentages of those who were convinced about the importance of ARVs were larger among those in school than those out of school. This implies that students in schools can

easily access information about ARVs through peer clubs, school authorities compared to those out of school

Adolescents fail adhere to ART due to perceived lack of effect; and this was reinforced by comments from one key informant who mentioned that, *"sometimes adolescents don't take pills and do not feel the effect which make them take it for granted"*. Adolescents who were in school were more knowledgeable about the benefits of drugs than those out of school This finding was supported by Nyambura (2009) who found that high levels of education increased adhered because they had better literacy skills and perception of the benefits of adherence to ART.

It was established that adolescents in this study drink mainly beer or spirits. Alcohol consumption was more among those who are out of school than those in school mainly because they are more permissive especially when they go out of school. Majority of the adolescents who take alcohol take it at least twice a week. The study also revealed that those who take alcohol were less likely to adhere to ARVs than those who don't take alcohol which implies that alcohol consumption interferes with adherence.

Perception of the benefits of ART was reported to affect adherence among adolescents. Key informants in this study reported that; *"misconception about drugs;" "attitude to treatment for example people who are fed up, those who feel well don't see the need to adhere;" having inconvenient school schedules that make it difficult to comfortably take drugs twice daily" being in the company of people who do not know why one is taking drugs or being with people who might ask why one is taking drugs;" "being tired of the routine of drugs;" "forgetfulness;" "Stress which is associated with chronic diseases;*" affect adherence to ART among adolescents. Other reasons given by key informants were; "*They live unique lives that include constantly taking drugs, routinely going to health facilities and being conscious of time for drugs. They may not freely make decisions to engage in relationships as they are thinking about infecting others."*
These findings agree with those of Bangsberg *et al.* (2004); and Kleeberg & Rudy (2007) who found that outcome expectancy regarding antiretroviral treatment enhances

adherence. The foregoing barriers were supported by Brogly et al (2005), who found that ART for HIV disease is often highly demanding, requiring multiple medications and frequent dosing.

5.1.3 Factors Related to School and Home of Adolescents on ART

It should be noted that there was no significant relationship revealed between home and school factors and adherence to ART (P>0.05), however the following findings were observed.

The study established that although water is necessary to facilitate swallowing drugs it is rarely available for this purpose. Nonetheless, there was a higher proportion of adolescents who were not in school (who reported having water than those in school. (Some adolescents had limited access to drinking water at all times thus accounting for poor ART adherence among both groups. School authorities need to ensure that drinking water is available in dormitories all the time. Schools should assign responsibilities to dormitory prefects to make sure that they boil enough water especially on weekends.

The other problem affecting adherence was noted by key informants. One of them had this to say, "Stress which is associated with chronic diseases" affects adherence to ART among adolescents". The findings support the observation of Mellins *et al; (*2006) who documented that adolescents who suffer from psychological disorders such as depression, stress and anxiety have low levels of ART adherence. When the mental health of adolescents is poor, they are most likely to lose hope, deny infection or even refuse to take their medication.

Most of the adolescents were willing to disclose their HIV status to either friends or teachers. As regards disclosure of their status to other family members, adolescents who were out of school were more open than those in school. Adherence levels were higher among those who were open and more willing to disclose this information to a third party than those who were less willing. This implies that if one discloses his/her HIV status to a trusted person, one can get encouragement, support and counselling which can help improve ones adherence. Some adolescents had revealed their HIV status to their teachers thus accounting for better adherence among school going adolescents than those out of school. These findings were similar to what Obarel (2006) reported that adolescents who

disclose their HIV status receive compassion /sympathy, counsel or help with medication, thus enhancing adherence.

Adolescents who were in school admitted that they were bothered by taking ARVs more than those who were out of school. This is because those in school are afraid of being stigmatised by their peers thus making it difficult to take the drugs privately since they stay in common dormitories and classes. These findings are similar to those of Ferris *et al* (2005) who found in their study that some adolescents often face denial of HIV status while others were afraid of taking drugs in the presence of peers due to stigmatization hence, failure to adherence to ART.

Some adolescents who were not in school had suspended taking drugs for several weeks before the study; others failed to adhere due to stigma and poor diet. This is because while it is a daily routine for schools to prepare meals for the students, some families stuggle to get enough food for both lunch and supper. Many families survive on one meal a day which is also of poor quality and can easily be foregone by the adolescents. The study also shows that adherence was higher among day scholars than boarding scholars. This finding is consistent with the findings of Ferris et al, (2005), Nabukeera et al. (2007); (Musisi, 2007); and Birungi (2009) who found that adolescents who attend boarding schools fail to adhere to ART because they fear to be stigmatised.

One key informant in this study mentioned *"self stigma and discrimination"* were barriers to adherence among adolescents on ART.

Lack of proper Mechanisms for health Care in schools

Adolescents reported that few schools offer peer support for HIV infected and affected adolescents and this contributes to poor adherence. Some adolescents in school are denied permission to go for ARV refills. This finding affirms what Lyon *et al*. (2003); and Birungi (2009) reported that school teachers and nurses lacked training in counselling and guidance; and noted that peer support in schools affects adherence among adolescents. It is therefore important for school authorities to provide counselling and guidance services including support for the affected students. This will go a long way in improving adherence.

Some adolescents mentioned that they failed to adhere due to lack of privacy. adolescentsThese findings were supported by Musisi (2007) and Birungi (2007) who also

observed that adolescents who attend boarding schools lack privacy while taking drugs and as a result, many of them fail to adhere to HAART because they fear to be stigmatised.

Some key informants attributed non-adherence to the following reasons; *"Having inconvenient school schedules that make it difficult to comfortably take the ARVs twice daily." Some children in school miss drugs because the school schedules coincide with times for taking drugs."*

On the other hand, those in boarding section reported that they rely on school nurses or friends to remind them. This finding was similar to the finding by Nabukeera et al, (2007) that adolescents in boarding schools may not have people to support and monitor them with adherence to regimens thus, accounting for poor adherence among adolescents.

Majority of adolescents who were either in school or those out of school could afford to eat at least twice a day. Only thirty-two percent of the study population could afford to eat three meals a day. These results depict poor nutrition among HIV adolescents and this affects adherence to ART Additionally, some adolescents in school and out of school cited lack of food as a barrier to adherence. One key informant identified lack of food as an obstacle to adherence. The issue of food was also reported by Nabukeera (2005) and Osterberg & Blaschke, (2005) who observed that some regimens require multiple and complex dosing schedules that may cause food interactions and these affect adherence levels especially among school-going adolescents who may not dictate meal-time schedules or diets.

The study identified parents and siblings as the primary caregivers of ART to adolescents but they also receive support from friends, guardians, grandmothers, siblings, matron and school nurses. The study found that both in and out of school adolescents who had other family members on ARVs tended to adhere better. One key informant was quoted as saying, '***children miss taking their drug because care takers are busy in one way or the other".*** These findings were supported by Steel & Chesney (2004) who found that the role of caregivers was affected by one's challenges, lifestyles and daily routines, hence impacting negatively on ART adherence. Whereas non school-going adolescents

reported that they received support from other family members, adherence among adolescents in this study was poor and this could be attributed to the challenges mentioned above.

One key informant reported that," foster parents at times take adolescents away from one home to another or even up country where they can`t access ARVs". Parents and care givers should always request for transfer out to another appropriate health centre in case they want to take the adolescents to another place. This problem can also be solved by securing of enough drugs that can sustain the respondent for the period he/she is away from the health centre.

5.1.4 Drug Related Factors

The commonest reason reported for non-adherence was side effects of the drug such as vomiting, nausea, itching and skin rash while key informants attributed non-adherence to dizziness, feeling abdominal fullness and anticipated or perceived side effects of the drugs.

Generally, adolescents who were in school (80.9%) had more barriers to adherence compared to those who were not in school (19.1%).

Adverse reactions to drugs were more common among adolescents in school than those who were not. Adverse reactions included unpleasant smell, nausea and vomiting among others. It was revealed that many school going adolescents suspended taking drugs due to adverse reactions than those who were out of school. Some school-going adolescents said they were not aware of the period they had suspended taking drugs

Results from one week self-report measure revealed that there were more adolescents in school than those out of school who adhered to ART during the one week self-report assessment. This is because majority of adolescents in school reported that they relied on their parents to remind them to take their medication. Whereas adolescents who were out of school receiving social support from other family members they reported the least number of adherentsadolescents ;and this could be attributed to what one key informant said; *"Having inconvenient school schedules that make it difficult to comfortably take the drugs twice daily ARVs"*

On the other hand, those in boarding reported that they depended on school nurses or friends to remind them. This finding was similar to the finding by Nabukeera et al, (2007) who reported that adolescents in boarding schools may not have people to support and monitor them with adherence to regimens thus accounting for poor adherence among adolescents. Schools should therefore employ more nurses proportional to the number of students they have to ensure that the infected students get enough care and monitoring

CONCLUSIONS AND RECOMMENDATIONS

6.1 Introduction

Adolescents gave various view of how they wish their adherence to ARVs could be enhanced by the concerned parties. This chapter shows the recommendations to health centres and health providers, school administrators (teachers, matrons and school nurses),

communities, homes and parents and to the adolescents themselves. The chapter also concludes the findings to the study.

6.2 **Conclusions**

The proportion of adherent adolescents in or out of school is less than that of non adherent ones who were on ART at Nsambya Home Care and Taso Mulago health facilities. The adherence was is affected by the distance one lives away from the health centre and religion, while factors like age, education level, gender among others, had no significant association with adherence. Availability of a person to remind the adolescents to take ARVs has a significant impact on adherence while factors like level of explanation, waiting time and privacy by the health workers have some effect though statistically insignificant. Stakeholder should therefore provide support to the adolescents in form of counselling, reminding, care among others so as to improve adherence levels

6.3 Recommendations

Health Centres and Healthcare Providers

In order to reduce on the high pill burden, pharmacists should provide injections in form of ARVs reduce on the size of the pill and provide one pill single dose. This can provide an alternative to those who are fed up with swallowing the pills. Every health centre should be strict and count the ARV`s on every visit.

Health centres should also conduct seminars for adolescents on importance of adherence and ARVs in order to change adolescents' perceptions about the drugs. They should involve adolescents in conferences about ARVs, provide encouraging messages on reasons for adherence and ARV`s and provide information on adherence on monthly basis.

To improve on counseling services, health centres should employ professional councilors and provide refresher courses to all their staff in guidance and counseling. In this the adolescents can get more attention and support which can improve on their adherence.

Health providers should also extend HIV services to schools and initiate peer support clubs; listen to their challenges and stop being hash or rude to them as this leads to missed appointments. Doctors should write a note to school teachers about the future clinic appointment.

School Administrators /Teachers, Matrons and School Nurses)

- The government should set a policy which necessitates every school to employ professional counselors to establish HIV counseling services in schools. Schools should also establish, support and guide HIV peer support clubs in schools, and allow adolescents go for their clinic visits.

- The infected adolescents need to be given special care in schools. This can be through giving them enough sleeping time and special meals. Boarding school matrons should open for students the dormitories to allow them swallow their ARV`s; provide adolescents with water for swallowing drugs; provide some food to eat before swallowing our ARV`s; and provide safe places to keep ARV`s not in public clinic.

- Schools should sensitize all their staff and non staff members about how adolescents should be treated and the importance of such treatment. Any teacher who fails to comply with the measures of confidentiality should be fired to deter others from doing so. This can help keep confidentiality and avoid discrimination, thus reducing on the effect of stigma among the adolescents. Teachers should give time to boarding students swallow their drugs not to rush the out of the dormitories and they matrons should open for them when they want to swallow their drugs. Sensitise teachers on the importance of ARV`s and attending the clinic visits.

Communities, Homes and parents

Local administrations should fund and establish HIV counseling services in communities. This can be through use of professional counselors who can visit homes of the adolescents, say, on a monthly basis.

Parents should provide alarm clocks; parents should remind and support adolescents take their ARV`s in time. Parents should also sensitize other family members about the importance of ARVs and how the adolescents should be treated. This can help reduce discrimination and avoid stigma in homes.

Parents should endeavor to provide adolescents with a balanced diet consistently. Some food to eat should be provided before swallowing ARVs in addition to safe drinking water for swallowing. Parents should also reduce on the adolescents' house work and allow them enough time to sleep and rest.

Communities should establish peer support clubs to allow free association of the adolescents with other adolescents. In these clubs peers can be educated and sensitized about

their role in supporting the adolescents, which can help reduce stigma.

6.4 Dissemination of Results

The results will be presented to the IHSU, Nsambya home care & TASO Mulago as well as conferences and publications in peer review journals.

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APPENDICES

1. **Consent form for above 18 children**
2. **Consent form for parent/guardian of child under 18**
3. **Assent form for an under 18 child.**

I hereby invite you to take part in a study titled "**Factors Affecting Adherence to Antiretroviral Therapy among Adolescents in or out of school Attending Nsambya Home Care and TASO Health Facility**".

Introduction
My name is …… I am part of research team from …….. IHSU, we are carrying out a study on above subject.

Procedure for the study
The study will involve asking you some questions concerning you and your adherence practices to. The interview will take approximately 15 minutes.

Benefit and risks
The result of this study is expected to improve management of ARV program among HIV/AIDS positive adolescents in or out of school.

There are no anticipated risks from the study; however, some questions may be difficult for you to answer. You are free to decline any such question that makes uncomfortable and this will not deny you any usual services you obtain here.

Confidentiality
All the information collected will be treated in confidence and used only for purposes of this study. It will be kept under key and lock and will be accessed by the investigator and the supervisor only. The dissemination of results will be by way of summarized information that will have no reference to any particular individual.

Rights of the participant
You are free to choose whether to take part in the study or not, and feel free to withdraw without loss of benefit at the clinic where you obtain care from at anytime. Feel free to ask the investigator, Ms Kangave Esther, at IHSU or on Telephone: 0712558734 for any questions concerning this study.
For any issues/questions concerning your right as a participant please contact Prof Ndugutse Mwajwejwe at International Health Science University, at Namuwongo and Phone 0772425924.

Statement of informed consent

I have read and understood the procedure, benefits, and risks of the study. I do here by voluntarily agree to participate in it.

Adolescents signature ……Date……
Witness :……Date ……..

Name of research assistant eliciting consent……
Signature……...
Date……..

Okukkiriza nga nnesaliddewo

Nsomye era ntegedde engeri okunoonyereza kuno bwe kugenda okukolebwa, emigaso n,obuzibu obuli mu. Nzikirizza okwetaba mu kunoonyereza kuno.

Nze akkirizza……
Amannya g'akola ku byokunyoonyereza ……..
Omukono gwe ……..
Ennaku z'omwezi…….....

Nzikirizza omwana wange okwetaba mukunoonyereza nga siwalirizibbwa
Ebinaaba bivudde mu byonna mbikirizza.

Nze ……omuzadde……

Omukono gw'omuzadde……Ennaku z'omwezi……

Adolescents' Questionnaire

Factors affecting adherence to antiretroviral therapy among adolescents in or out of school

Questionnaire number: …….....
Date of interview: ……
Interviewer: …….
Interviewee No: ……...
Name of HAART site ……...

First identify by asking: Are you in school?

1. Yes
2. No

Section A: **Individual factors/socio demographic characteristics**

1. Age

1. 10-14 years ☐ 2. 15-19 years ☐

2. Sex of client?

1. Male ☐ 2. Female ☐

3. Are you attending school presently?

1. Yes
2. No

If no, go to question 5

4. If you are in school what is level of your education

1. Primary level ☐
2. Ordinary level ☐
3. Advanced level ☐
4. Tertiary level ☐

5. Religion

1. Catholic ☐
2. Protestant ☐
3. Moslem ☐
4. Other (Specify)……

6. School section

1. Boarding ☐
2. Day ☐

7. Does your school offer peer support for HIV infected and affected students?

1. Yes ☐

2. No ☐

8. Does your school or care giver readily provide you with permission each time you request to visit a health facility to refill your ARV?

1. Always ☐

2. Sometimes ☐

3. Never ☐

9. Do you have readily available water each time you may need to swallow your drugs?

1. Always ☐

2. Sometimes ☐

3. In most cases no water ☐

10. What is the average number of meals available per day?

1. Once ☐

2. Twice ☐

3. Three times ☐

10b. If NO, how do you get your meals.....?

Section B: **Medicine related factors**

11. How long have you been taking HAART?

1. 6 months ☐

2. 7-12 month's ☐

3. 13-24 month's ☐

4. 24 months ☐

12. Have you experienced any adverse reactions to those drugs?

1. Yes ☐

2. No ☐

13. If yes, did you suspend swallowing your medicines as a result?

3. Yes ☐

4. No ☐

…….

14. Are you on any drugs currently?

1. Yes ☐

2. No ☐

14b. If no, why..... and for how long……?

15. If yes, what drug……...?

16. Have you missed taking ARVs at any time?

1. Yes ☐

2. No ☐

17. If yes, number of times missed ……..average period of time ……

18. Why did you miss taking your pill? ☐

1. Forgot to take the pills. ☐

2. Got side effects:

- Skin rash/itching ☐
- Nausea/vomiting ☐
- Headache ☐
- General body weakness ☐
- Fever ☐
- Other (specify) ……

3. Perceived or actual lack of effect ☐

4. Lack transport fare ☐

5. I was instructed by the health care provider not to take. ☐

7. Other (specify) ……..

19a. Does taking ARV`s bother you in any way?

1. Yes ☐

2. No ☐

19b. If yes, how ……

Section C: **Client related factors**

20. Do you have a boy/girl friend?

1. Yes ☐

2. No ☐

(20b) If yes, do you ever have sex together?

1. Yes ☐

2. No ☐

21. If yes, do you know his /her HIV status?

1. Yes ☐

2. No ☐

22. Does he/she know that you are taking ARV?

1. Yes ☐

2. No ☐

23. Do other members of your family know about your HIV status?

1. Yes ☐

2. No ☐

24. Are there other people taking ARV in your home?

1. Yes ☐

2. No ☐

25. Do teachers in your school know about your HIV status?

1. Yes ☐

2. No ☐

26. Do you pay for ARVs or are they free?

1. Pay ☐

2. Free ☐

27. Do you drink alcohol?

1. Yes☐

2. No ☐

(27b) If yes which type of alcohol.....?

28. If yes, how frequent do you drink?

1. Every day ☐

2. Three times a week ☐

3. One to two times a week ☐

4. Less than two times a week ☐

29. How much alcohol do you drink (quantify in 500ml beer bottles)……?

30. Do you think a person with HIV/AIDS can benefit from these drugs?

1. Yes ☐
2. No ☐
3. Do not know ☐

31. Share more reasons for taking this drug?

1. To cure me of HIV/AIDS ☐
2. To alleviate the symptoms and improve my health ☐
3. Just for consolation that at least I am taking some medication ☐
4. Other (specify)……..

32. Do you think if you miss some doses it has an effect on your health?

1. Yes ☐
2. No ☐
3. Don`t know

33. If yes, how……?

Section D: **Health service delivery factors**

34. How far is the treatment site from your home?

1. < 5Km ☐
2. > 5Km ☐

35. Do you wait for long (>30 min) before seeing the doctor or getting medicine?

1. Yes ☐
2. No ☐

36. If yes, has this ever made you miss your medicine?

1. Yes ☐
2. No ☐

37. Do you sometimes miss getting medicines?

1. Yes ☐
2. No ☐

38. Does the health facility provide you with privacy when consulting health workers?

1. Yes ☐

2. No ☐

39. Do you perceive the health care providers allow you enough time to talk to them?

1. Yes ☐

2. No ☐

40. Do health workers explain to you that these drugs must be taken consistently?

1. They do so always ☐

2. They do some times ☐

3. They never do so ☐

41. Are the drugs always available whenever you go for them?

1. Yes ☐

2. No ☐

42. Do you have another source of ARV?

1. Yes ☐

2. No ☐

43. If yes, where…….

44. Did you receive counselling initially before you started on ARV?

1. Yes ☐

2. No ☐

45. Do you receive counselling each time you come for ARV?

1. Yes ☐

2. No ☐

46. do you have someone who administers or reminds you take you're the ARV`s?

1. Yes ☐

2. No ☐

47. If yes, who…….

Section E: **Adherence**

48. Client self-reports on a five-dose pill intake:

a) Adherence yesterday.....

b) Adherence in the last five days.....

Doses actually taken in the last 5 days X 100 =

No. Of doses in the last 5 days

c) Adherence in the last one wk

Doses actually taken in the last 1 wk X 100 =

No. of doses in the last 1 wk

49. Adherence by pill count in the clinic

No. Of pills actually taken X 100 =

doses that must have been taken

50. Suggest possible ways of improving adherence among in or out of school adolescents

.....
.....
.....
.....
....

That is the end of the questionnaire. Thank you very much for your help in answering these questions. We greatly appreciate your help and hope you felt able to answer the questions without too much trouble.

(To interviewer: Check to make sure the questionnaire is completely filled, then thank the respondent for her/his time and information).

Key interview informants' guide for caretakers and health providers from Nsambya and TASO

1. What problems do HIV/AIDS clients encounter?
2. Some clients miss taking medicines as instructed by the health care provider, why do you think this happens?
3. What do you think are clients' related factors that affect adherence to ARV? (probe)
4. What do you think are medicine related factors that affect adherence to ARV? (probe)
5. How can adherence to ARV among in or out of school adolescents' be improved?
6. In your` experience, who are more likely to be non-adherent: in school or out of school adolescents? .....

ENSONGA EZILEMESA ENKOZESA ENUNGI EYE DDAGALA ELIWEWEZA KUKAWUKA MUBAVUBUKA ABASOMA NA`BATASOMA.

Omuwendo gwo`lupapula olubuli zibwa ko……..,……..

Olunaku lwo` mwezi olibuzidwako/olokugezeza ko……

Omugezesa (abuuza ebibuuzo)……

Omuwendo gwo`yo age zesebwa…….

Elinya lyekifo mwafunira eddagala……..

Sooka ononyeleze nga': nti olimusomero? Oba osoma?

1. Yee ☐

2. Nenda ☐

Akatundu akasooka ezikwata ku seno muki

1. Emyaka

1. 10-14 ☐

2. 15-19 ☐

2. Ekikula kyo`yo gwo buuza

1. Mulenzi ☐

2. Muwala ☐

3. Mukiseera kino osoma?

1. Yee ☐

2. Nedda ☐

Bwa`ba tasoma genda kukatundu oku`kutaano (5)

4. Bwo`ba Nga osoma, oli ku ddala ki?

1. Kuddala elya pulayimale (elisooka) ☐

2. Elyokusatu ☐

3. Elya ddiguli ☐

5. Enzzikiriza ☐

1. Mukatuliki ☐

2. Mukulisitayo ☐

3. Musilamu ☐

4. Oba enzikiliza endala (ginyonyole).....

6. Akatundu ake` bye nsoma

1. Mukisulo ☐

2. Ova waka nogenda kusomero ☐

7**.** Essomero mwo`somera liyamba okukunganya no` kugatta abayizi abalina akawuka akaleta mukenenya wamu nabo` abakosedwa? Oba abakwatiibwako?

1. Yee ☐

2. Nedda ☐

8. Essomero gyo`somera oba oyo akulabilira ,akukiriza okugenda okufuna eddala lyo okuva mudwaliro gyo`lifunira buli lwo saba okuddayo okulifuna?

1. Bulijjo ☐

2. Olumu nolumu ☐

3. Tanzikiiriza ☐

9. Ammazzi agokumirisa eddagala lyo obeera nago?

1. Bulijjo ☐

2. Lumu nalumu ☐

3. Emilundi egisinga tegaberawo ☐

10. Emirundi emeka gyo`tela okulya mu emmere buli lunaku?

1. Gumu ☐

2. Ebiri ☐

3. Esatu ☐

4. Bwewaba nga tewali, okola otya okufuna emmere eyo kulya……..?

AKATUNDU B: Ensonga ezikwata kuddagala

11. Ebanga ki lyo maze nga omila eddagala eliweweza kukawuka?

1. Emyezi mukaaga (6) ☐

2. Muasanvu okutuuka ku kumi nebiri (7-12) ☐

3. Kumi nessatu kotuuka kubiri mwena (13-24) ☐

4. Myezi abiri mwena (24) ☐

12. Ofunye yo obuzibu bwonna nga buva kuddagala elyo?

1. Yee ☐

2. Nedda ☐

13. Oba yee, wayimiriza mu okumilira eddagala lino olwe `byo ebyavamu?

1. Yee ☐

2. Nedda ☐

14. Olina eddagala lyona ly` mila mukiseera kino?

1. Yee ☐

2. Nedda ☐

3. Oba nedda, lwaki.....ela banga kilyo`maze nga tomira.....?

4. Oba yee, ddagala ki.....

16. Olina lwe wali oyosezza mu okumila eddala lino eli weweza kukawuka?

1. Yee ☐

2. Nedda ☐

17. Oba yee,emirundi emeka gye wayosa.....banga ki.....

18. Lwaki wayosa okumila eddala lino? ☐

1. Nerabira okumila ☐

2. Nalifuna mu obuzibu ☐

Nabutuka olususu/no kuyisibwa ☐

Okusindukilirwa emeeme / okusesema ☐

Okulumwa omutwe ☐

Obunafu mu mubiri ☐

Omusujja ☐

Ebilala, (Nyonyola).....

3. Okubulwa etambula ☐

4. Omusawo ya ndagila obutamila ☐

5. Ebilala (nyonyola).....

19. Okumila eddagala eli weweza kukawuka,kilina engeri gye kikutawanya mu?

1. Yee ☐

2. Nedda ☐

Obayee,kitya?.....

AKATUNDU C: EBIKWATA KWO`YO GWO` BUUZA (abuuzibwa)

20. Olina mugazi wo nga muwala oba mulenzi?

1. Yee ☐

2. Nedda ☐

B) Oba yee,mwali mwegasse ko mubyo mukwano?

1. Yee ☐

2. Nedda ☐

21. Oba yee,omanyi oba alina akawuka oba talina?

1. Yee ☐

2. Nedda ☐

22. Akimanyi ko nti omila eddagala eliweweza ku kawuka?

1. Yee ☐

2. Nedda ☐

23. Abalala abo`mukago oba bookela nabo, bakimanyiko nti olina akawuka akaleeta mukenenya oba tolina?

1. Yee ☐

2. Nedda ☐

24. Mu Bantu boobela naba, awaka, waliwo omulala amila eddagal lino?

1. Yee ☐

2. Nedda ☐

25. Abasomesa kussomera gyo`somera bamanyi kubi kwata ko nti olina akawuka oba tolina?

1. Yee ☐

2. Nedda ☐

26. Eddala lino eliweweza ko akawuka,oligula?oba ofuna lya bwerere?

1. Nsasula ☐

2. Lya bwerere ☐

27. Onywa omwege?

1. Yee ☐

2. Nedda ☐

b) Oba yee,kika ki ekyo mwenge kyo` nywa.....

28. Oba yee,kika ki ekyo mwenge kyo` nywa.?.....

(Emirundi emeka)

1. Buli lunaku ☐

2. Emirundi essatu (mu sabbiti emu ☐

3. Gumu oba ebiri mu sabbiti emu ☐

4. Wansi we mirundi ebiri mu sabbiti emu ☐

29. Olowooza onywa kipimoki ekyomwenge (obungi, cupa za biya meka)?
bottles)……?

30. Olowooza omunti alina akawuka akaleeta mukenenya obba silimu, eddagala lino lilina kyelimugasa?

1. Yee ☐

2. Nedda ☐

3. Simanyi ☐

31. Wayo ensonga endala lwaki eddagala lino limilibwa?

1. Kumponya akawuka akaleeta mukenenya /silimu ☐

2. Okujjawo obubonero no'kulongoosa embeera yo bulamu bwange ☐

3Okwezamu amanyi nti kasita nina eddagala lye mmila ☐

4. Ebilala (nyonyola)……..

32. Olowooza bwo'yosamu mu kumila eddagala kulina engeli gyekikosa mubulamu bwo?

1. Yee ☐

2. Nedda ☐

3. Simanyi ☐

33. Bwekibanti yee, kikosa kitya? .....

……?

AKATUNDU D: **Ensonga ezikwata kungeli obujjanjabi gyebuwebwamu?**

34. Buwanvu ki, obwolugendo okuva wo'bera okutuka wofunila eddagala?

1. Wansi wakilomita tanu (5) ☐

2. Waggulu wa wakilomita tanu (5) ☐

35. Olinda ebanga ddene okusuka mu dakiika asatu nga'tonalaba musawo oba okufuna eddagala?

1. Yee ☐

2. Nedda ☐

36. Bwekiba nti yee, kino kyalikikuletedeko okuyosa okufuna eddagala lyo?

1. Yee ☐

2. Nedda ☐

37. Emirundi egimu oyosa okufuna eddagala?

1. Yee ☐

2. Nedda ☐

38. Edwaliro mwofunila eddagala, likuuma ebyama oba likuwa obukuumi bwoba nga webuuza ku basawo?

1. Yee ☐

2. Nedda ☐

39. Owulila nti abasawo bakuwa obudde obumala okwogela nabo?

1. Yee ☐

2. Nedda ☐

40.Abasawo bakunyoyola nti eddagal lino litekedwa okumilibwa obutayosa oba awtali kwosa?

1. Bulijo bakikola ☐

2. Bakikola lumunalumu ☐

3. Tebakikola ☐

41. Buli lwogenda okufuna eddagla, libelawo?

1. Yee ☐

2. Nedda ☐

42. Olinako awalala wofunila eddagala lino eliweweza kukawuka?

1. Yee ☐

2. Nedda ☐

43. Bwekiba nti yee, kifoki?…….

44. Wafuna okubudabudibwa oba okusomesebwa nga to'natundika kumila ddagala lino eliwewezako akawuka kamukenenya?

1. Yee ☐

2. Nedda ☐

45. Ofuna okubudwabudibwa /oba okusomesebwa buli lwogenda ofufuna eddagala lino?

1. Yee ☐

2. Nedda ☐

46. Olina omunti akuwa eddagala oba okukujjukiza okumila eddagala lino eliwewezako akawuka?

1. Yee ☐

2. Nedda ☐

47. Bwekiba nti yee, ani akikola…….

AKATUNDU E: **Enkozesa ennungi eyeddagala**

48. Ebikwata ku abuuzibwa, engeli gyamilamu eddagala emirundi etaano:

A = Ebipimo bye ddagala elimilidwa munaku ettano

B = Ekipimo kyatekedwa okumila okusinzila nga abasawo bwe bamulagila

Enkozesa ye ddegala ennungi = (A/B) X100

49. Ekipimo ekigelagelanyizibwa oba ekyenkanankana wakati wa zeero okutuuka ku kikumu ku kikumi(0 – 100%):

abuuza ebibuuzo alaga omuntu ga omuntu engeli gyayina okugelagelanya enkozesa ye bipimo bye bya'kozesa nga amila eddagala lye nga akozesa ekipimo kye naku assatu.....

Ela ayambibwako okwepima nga bwe yamila eddagala nga akozesa ekipimo kino mubbanga elyo'mwezi ogwayita.

50. Wayo amakubo engeli omutindo gwo kumila eddagala bwe gunalo ngosebwa mubavubuka abasomera mukisulo wamu naabo abava awaka okugenda kusomero.

Eno ye nkomelero yo'kubuuzibwa kuno. Webale nyo olwo buyambi bwo'koze nga oddamu ebibuuzo. Tusiimye nyo era tusuubira nti obadde nobusobozi okuddamu ebibuuzo nga tofunyemu nnyo buzibu?

Eri omugezesa oba abuuza ebibuuzo: kebela era okakase nti olupapula lwe bibuuzo lwona lujjuzidwa ela webaze azzemu ebibuzo olwobudde bwe na mawulire bya'kuwadde.

Ebikulu mugezesa abawayo amawulire age`kyama kubi bakwatako,okulungamya, abajjajabi na`basawo okuva Nsambya ne TASO.

1. Bizibu ki abantu abalina akawuka no` bulwadd e bwa mukenenya bwebasanga?

2. Abantu abamu (abalwadde) bayosa okumila eddagala okusinzila nga bwe baba balagiddwa abasawo, olowooza lwaki kino kibawo?

3. Bintu ki, byo lowooza ebivako abalwadde obutamila bulungi eddagala lya ARV? (byebiriwa)

4. Buzibu ki, bwo lowooza nti buva kumila yeddagala lya ARV ? (binyonyoleko)

5. Enkoseza yeddala mubavubuka abasoma nabatasoma , ene longoosebwa etya?

6. Okusula…kubumanyilivu bwo,baani abayinza okubanga tebamila bulungi ddagala, abavubuka abasoma? oba abatosooma? .....

APPENDIX II

Work plan

Activity description	Timing (2012)								Person (s) responsible
	Mar	Apr	May	June	July	Aug	Sept	Oct	
Develop proposal									PI, SP
Proposal approval									IRB
Pretest study tools									PI, RA
Collect data									PI, RA
Enter and clean data									PI
Analyze data									PI
Write report									PI
Submit report									PI
Disseminate report									PI

Key: PI = Principle Investigator; SP = Supervisor; RA = Research Assistan

APPENDIX III

Budget

Activity Code	Activity Description	Resource	Quantity	Frequency	Unit cost	Amount
A: 1	Develop proposal	Printing	1	5	37,500=	187,500=
		Photocopy	350	1	1,000=	35,000=

	Sub-total					**222,500=**
A: 2	Train 8 research assistants	Meals	8	2	10,000=	160,000=
		Transport	8	4	20,000=	640,000=
		Stationary	8	1	5,000=	50,000=
	Sub-total					**850,000=**
A: 3	Pretest study tools	Meals	1	1	5,000=	5,000=
		Transport	1	1	20,000=	20,000=
		Allowance	1	1	5,000=	5,000=
	Sub-total					**30,000=**
A: 4	Collect data	Meals	8	10	10,000=	800,000=
		Transport	8	10	10,000=	800,000=
		Allowance	8	10	5,000=	400,000=
	Sub-total					**2,000,000=**
A: 5	Report writing	Printing	10	1	37,500=	375,000=
		Photocopying	10	1	7,500=	75,000=
		Binding	10	1	10,000=	100,000=
	Sub-total					**550,000=**
A: 6	Dissemination of reports	Photocopy	5	1	7,500=	37,500=
		Binding	5	1	50,000=	250,000=
	Sub-total					**287,500=**
Grand Total						**3,940,000=**