

**CARE GIVER FACTORS ASSOCIATED WITH ADHERENCE TO ANTIRETROVIRAL
THERAPY AMONG HIV INFECTED CHILDREN AT KISUGU HEALTH CENTRE III**

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**AN UNDERGRADUATE RESEARCH REPORT SUBMITTED TO THE SCHOOL OF
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DECLARATION

I, Echiru Andrew, do hereby declare that, to the best of my knowledge, this dissertation is my original research work. Everything in this research paper is as a result of my hard work through reading various literature including my personal knowledge and interpretation of the contents of the topic in the field of research under the guidance of my supervisor.

I am therefore certain that no work of this kind has been produced or submitted to this University or any other institution of higher learning for an academic qualification.

I henceforth present it for the award of a Degree of Bachelors of Nursing Science of International Health Sciences University.

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APPROVAL

I hereby declare that the content of this research report has been done through my supervision and has been submitted to School of Nursing at International Health Sciences University with my approval as the candidate's supervisor.

I certify that I have read this research report and that in my opinion it is fully adequate, in scope and quality, as an undergraduate thesis for the award of a degree of Bachelor of Nursing Science.

.....

MRS. OKECHO FLORENCE
(Supervisor)

.....

Date

DEDICATION

To GOD who has helped me overcome all the challenges I encountered during this research period and to my beloved parents Mr. Echiru John William and Mrs. Echiru Jackline who sacrificed a lot and spared nothing in my upbringing and enabled me to attain valuable education.

Also my dear friends and family for their support and courage towards my academic endeavors. I really appreciate.

Thank you so much!

May GOD reward you abundantly.

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However none of the above should be held responsible for the views, opinions and conclusions in the study. I am solely responsible for all that has been presented.

May God Bless You All.

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OPERATIONAL DEFINITIONS

Adherence: Adherence is “the extent to which a person’s behavior taking medications, following a diet and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider” (WHO).

Non-Adherence: Means not following the prescribed treatment plan and includes missed or delayed doses or failing to follow guidelines like, taking too little or too much medication and taking it at incorrect times.

Level of adherence: Refers to the extent at which patients on ARV’S correctly take their medication up to the expected percentage by the Ministry of Health

Primary Caregiver: This refers to a person who has consistently assumed responsibility for the health, housing or safety of the child (individuals who administered at least 50% of the child’s treatment daily and bringing the children for clinic appointments).

Factors: These are circumstances, facts, or influences that contribute to a result or outcome. These are the driving cause for non-adherence to ART treatment among HIV infected children.

Sero positive: Refers to one who is HIV positive

LIST OF ACRONYMS

ACP :	AIDS CONTROL PROGRAMME
AIDS:	ACQUIRED IMMUNE DEFICIENCY SYNDROME
ART :	ANTIRETROVIRAL THERAPY
ARV :	ANTIRETROVIRAL
AVERT:	AIDS EDUCATION AND RESEARCH TRUST
HIV :	HUMAN IMMUNE DEFICIENCY VIRUS
IHSU :	INTERNATIONAL HEALTH SCIENCES UNIVERSITY
KCMU :	KILIMANJARO CHRISTIAN MEDICAL UNIVERSITY
MOH:	MINISTRY OF HEALTH
PLWHIV:	PEOPLE LIVING WITH HIV
TCA :	TANZANIA COMMISSION FOR AIDS
UAC :	UGANDA AIDS COMMISSION
UDHS :	UGANDA DEMOGRAPHIC AND HEALTH SURVEY
UNAID:	UNITED NATIONS AID.
UNICEF:	UNITED NATIONS CHILDREN'S FUND
WHO:	WORLD HEALTH ORGANIZATION

ABSTRACT

Background:

Adherence to ART among children is a dynamic challenging process involving several factors. With use of effective ART therapy, survival of children with AIDS has extensively increased but the benefits of this therapy are limited by non-adherence. This study aimed at establishing the caregiver factors associated with adherence to ART among children infected with HIV at Kisugu Health Center III.

Methodology:

The study was carried out using a cross – sectional descriptive study design. The design used only quantitative methods of data collection while in the field and the study population included only caregivers of HIV sero – positive children at Kisugu Health Center III ART clinic by the time of the study and its where a sample of 188 respondents were selected by means of simple random sampling technique. Data was collected with use of pretested and structured questionnaires. Descriptive and summary statistics were employed. Uni-variate and Bi-variate logistic regressions and their 95% confidence intervals were computed to determine the level of statistical significance.

Results:

Less than half 40.4% of the caregivers indicated that their children were adherent to ART therapy in the last week preceding the interview. The study found out that primary caregivers relationship with the child ($P=0.039$), primary caregivers level of education ($P=0.010$), Social support ($P=0.043$) and ART counseling services ($P=0.000$) were independently associated with adherence. None of the treatment related factors was statistically significantly associated with adherence to ART among children.

Conclusion

Only 59.6 %(112) of pediatric patients had good adherence to ART in the previous week prior to study start. The fact that the primary caregiver was a parent of the infected child adversely affected adherence whereas adherence rates were seen to increase with increasing primary caregiver level of education.

Recommendations

Caregivers should be educated and provided with appropriate and accurate information on HIV/AIDS and about ART therapy as well as encourage support groups since social support improved adherence to ART therapy. There is thus need for assessments of the caregiver's education level, relationship to the child and provision of social support and ART counseling services in an effort to ensure improved adherence to ART at Kisugu Health Center III.

CHAPTER ONE:

1.0 Introduction

This chapter examined the background of the study, problem statement, study justification, the main objectives, specific objectives, and the research questions, significance of the study and the conceptual frame work of the study.

1.1 Background of the study

Adherence is “the extent to which a person’s behavior taking medications, following a diet and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider” (WHO). Adherence to ART medication regimen is one of the most vital indicators of survival for people with HIV/AIDS. The advent of ART has significantly slowed down the progression of HIV, reduced the death rate from AIDS and transformed the infection from a fatal illness to a more manageable chronic illness. However, simply making ART medicine available to PLWHIV is not enough, as strict adherence is required for treatment success.

Prescribers hope that every patient completely follows their ART instructions, but the literature shows that a proportion of PLWHIV do not take medications as prescribed for various reasons. A patient’s ability to adhere to medication is greatly influenced by both individual and environmental factors. Several studies have shed light on the factors associated with adherence, highlighting socio – demographic, cultural, economic, health-systems and treatment-related factors (*Nachega JB, et al., 2009, Hardon et al., 2010*).

HIV/AIDS needs long-term treatment although adherence to treatment is believed to decrease with time. The exercise is tedious for patients taking daily medication and in eight months, compliance to medication was shown to decrease significantly (*Osterberg L,et al., 2015*). To consistently follow treatment recommendations, adherence requires dedication of both the caregivers and the children. [Shah CA, et al., 2009). Not only do the child and caregivers need to be committed to treatment, but a variety of other factors may complicate ART adherence in children.

Globally, an estimated 1.1 million adults died of AIDS non-adherence related deaths although 41% of adults were accessing ART (UNAIDS, 2015). In North America estimated 55% adults, achieved over 80% adherence [WHO, 2016]. World wide access to ART has increased tremendously changing the clinical course of HIV/AIDS with significant decline in morbidity and mortality hence shifting the challenge from access to adherence. A study conducted by *Herek GM, et al., (2008)* showed that the proportions of non-adherent adults living with HIV/AIDS who have access to ART therapy are 58% in Nepal, 64% in India and 80% in Bangladesh. Most studies have shown low levels of adherence in resource limited countries (*Srikrishnan AK, et al 2010, Bisson, et al., 2008*), support groups and society acceptance of adherence behaviors have attributed to these efforts.

Worldwide, 32 % of children were accessing ART therapy, (UNAIDS 2016). A third of children living with HIV without treatment, die by their first birthday and half die by their second. A review by *Gisore et al.,* on pediatric ART adherence in developing countries, revealed that majority of studies on pediatric adherence to ART levels indicated a range of 44% to 100%, with 86% of articles reporting greater than 75% adherence while in another study by *Smith et al.,* estimates of pediatric adherence to ART levels from developed countries ranged even more widely from 25% to 100%. Sustaining good adherence to ART in children is difficult as it is influenced by several caregiver factors such as age, gender, marital status, social support, financial status and level of education (*Nemes, et al., 2014*).

Africa has 7.6 million adults, receiving ART treatment and nearly 76% of them are adherent as of December 2014 (UNAIDS). The percentage of people living with HIV who are receiving antiretroviral therapy and are non-adherent has been reduced from 90% in 2006 to 63% in 2013 (WHO). In Africa estimated 77% of adults achieved over 80% adherence [WHO, 2016]. The adherence rates among women were also marginally lower 84 % versus 86 % among men where as 34% of adults died of HIV/AIDS, non-adherent related causes in 2013(UNAIDS, 2013).

In sub-Saharan Africa among 2.9 million children living with HIV/AIDS, 24% were receiving ART and 76% of children living with HIV were not adherent to HIV treatment (*Murri et al., 2012*). A study done in Botswana revealed that pediatric adherence rates were of 75 % respectively (*Weiser et al 2013*) where as moderately lower pediatric levels of adherence of 66% were reported in a study conducted by *Byakika et al (2008)* in Uganda. This indicates that, as opposed to expectations, pediatric adherence levels in Africa are favorable. Nonetheless, with increased pill fatigue given increments in time of

exposure, and with a goal towards universal access that will bring individuals with adherence challenges on board, it is improbable that these favorable rates will persist.

Many resource poor countries have a high rate of non-adherence among children infected with HIV, and are on ART (Haberer J, et al., 2009). A study conducted by Haberer J, et al .,(2009) at KCMC, revealed that around 25% of 300 children are on second line regimen treatment following failure of the first line regimen, citing non adherence to ART therapy and in 2009 only 65.2% of the 425,735 children who received treatment ART treatment were adherent (TCA, 2009).

In Uganda, an estimated 69.4% of 1.6 million adults living with HIV/AIDS were accessing ART. As of 2013 more than 60% of adults living with HIV were non adherent to treatment hence an estimated 63,000 adults died of AIDS non adherence related illnesses (WHO, 2013). A study in 2013 reported 1,478 health facilities in operation in Uganda offering ART and that by 30 September 2013; nearly 800,000 adults living with HIV were enrolled on treatment. The proportion of adults living with HIV that were on treatment by the end of September 2013 in Uganda and were adherent to treatment was 40% (UAC, 2014).

Uganda registered a treatment adherence rate of over 90% among children (WHO 2015). Using unannounced pill counts, one study reported good adherence levels among Ugandan children; Poor adherence was found to be more common in situations where a child's HIV status was only known to the primary caregiver (Kalyesubula et al., 2009). The findings of this study, however, were questioned because children on syrups and suspensions were excluded. In Uganda, children often are cared for by grandparents or elderly neighbors who may have their own health challenges and are often further impoverished by the children's lack of income. The ACP reports for the quarters Jan-Mar and April-Jun 2014 indicate that overall ART adherence at 12 months of follow up was about 85% but for the quarter ending September 2014 there was a decline to 75% with marked regional difference.

The UDHS report revealed that although Kisugu Health Centre III had good supply of antiretroviral drugs, poor adherence to treatments among children who do not abandon their ART treatments and high HIV/AIDS related stigma levels among children was noted. The on and off interruptions in ART treatment result in drug resistance. Good adherence to ART is critical for achieving viral suppression and good clinical outcomes.

1.2 PROBLEM STATEMENT

Unpublished reports at Kisugu Health Center III indicate that the challenge of adherence is mostly manifested through high defaulting levels ranging from 11 – 30 % with 16% to 26% of the children on ART being lost follow up within three years of starting ART. This is worsened by lack of efforts by health care providers to assist the caregivers through provision of advice or information by adequately counseling the caregivers about ART therapy. Adversely the issues outlined by *UAC, (2010)*, related to pediatric ART adherence included high levels of non-adherence to treatments among children who do not abandon their ART treatments with a high loss to follow ups of mobile populations on treatment. The *UAC reports, (2010)* indicate that the burden of offering ARV's is very high resulting from insufficient human resources thus increasing waiting time for the caregivers hence poor health care provider client relationship.

Despite efforts by non – governmental organizations like Baylor Uganda, who have in place assessment mechanisms of adherence to ART by using appropriate assessment tools using methods such as patient self-reports, pill counting, Medication event monitoring system, Directly Observed Therapy, and plasma ART drug level assays, there is still a big gap as of today in most Ugandan health institutions and facilities, on the review dates patients are not given specific hours of appointment. Furthermore, electronic dispensing is rare in the health facilities because of its associated technological challenges.

Non adherence to ART medication regimens has serious outcomes for HIV/AIDS infected children, which include failure to prevent viral replication and an increased risk of developing viral resistance, the development of clinical complications, and shortened survival. Hence leads to increased use of medical resources, such as physician visits, laboratory tests, unnecessary additional treatments or more costly treatments and escalates adverse events. Non adherence can lead to the need for expensive second and third line treatments in patients who may have initially controlled the infection.

To strengthen adherence to ART among HIV-infected children, it is indispensable to identify caregiver factors that are associated with adherence and to look at the possible interventions to improve pediatric adherence to ART therapy. This study will therefore determine the caregiver factors associated with adherence to ART among HIV infected children at Kisugu health center III.

1.2 STUDY JUSTIFICATION

The ability of children infected with HIV/AIDS to adhere to ART is fundamental to delay resistance and guarantee lifelong effective treatment. Vulnerable groups such as children need special attention by health workers and policy makers. Different studies in Africa context indicated that there is a deficit in the level of adherence of children to ART and multiple factors have been mentioned to contribute to the existing gap. This study will provide caregiver related factors on the level of adherence of HIV infected children in Ugandan context. Nonetheless, it will provide important information with regard to aspects of adherence and forward recommendations to health care providers, health facilities and policy makers in enhancing the implementation of ART program and development of evidenced-based interventions to improve adherence to antiretroviral therapy among HIV infected children.

1.3 OBJECTIVES

1.3.1 Major Objective

To establish the caregiver factors associated with adherence to ART among children infected with HIV at Kisugu Health Centre III between August and September 2016 so as to improve pediatric adherence to ART therapy.

1.3.2 Specific Objectives

- i. To determine the rate of adherence to antiretroviral therapy among HIV infected children at Kisugu Health Centre III between August and September 2016.
- ii. To determine the socio demographic characteristics of the care givers associated with adherence to antiretroviral therapy among HIV infected children at Kisugu Health Centre III between August and September 2016.
- iii. To identify the health care system related factors of the care givers associated with adherence to antiretroviral therapy among HIV infected children at Kisugu Health Centre III between August and September 2016.
- iv. To assess the treatment related factors of the caregivers associated with adherence to antiretroviral therapy among HIV infected children at Kisugu Health Centre III between August and September 2016.

- v. To identify psychosocial factors of the caregivers associated with adherence to antiretroviral therapy among HIV infected children at Kisugu Health Centre III between August and September 2016.

1.4 RESEARCH QUESTIONS

- i. What proportion of children with HIV/AIDS adheres to ART at Kisugu Health Centre III?
- ii. What are the caregiver socio demographic characteristics associated with adherence to antiretroviral therapy among HIV infected children at Kisugu Health Centre III?
- iii. What are the health care system related factors of the care givers associated with adherence to antiretroviral therapy among HIV infected children at Kisugu Health Centre III?
- iv. What are the treatment related factors of the caregivers associated with adherence to antiretroviral therapy among HIV infected children at Kisugu Health Centre III?
- v. What are the psychosocial factors of the caregivers associated with adherence to antiretroviral therapy among HIV infected children at Kisugu Health Centre III?

1.5 SIGNIFICANCE OF STUDY

This research work is significant for the following reasons:

This research breaks the silence on adherence by creating awareness on the topic and the impact it has on children and promoting integration of ART treatment plans among children in health and hygiene sectors of the Ministry of Health.

This study discusses ways of supporting adherence campaigns among children, by informing the society the need for children to access and be adherent to ART so as to enhance their quality of life.

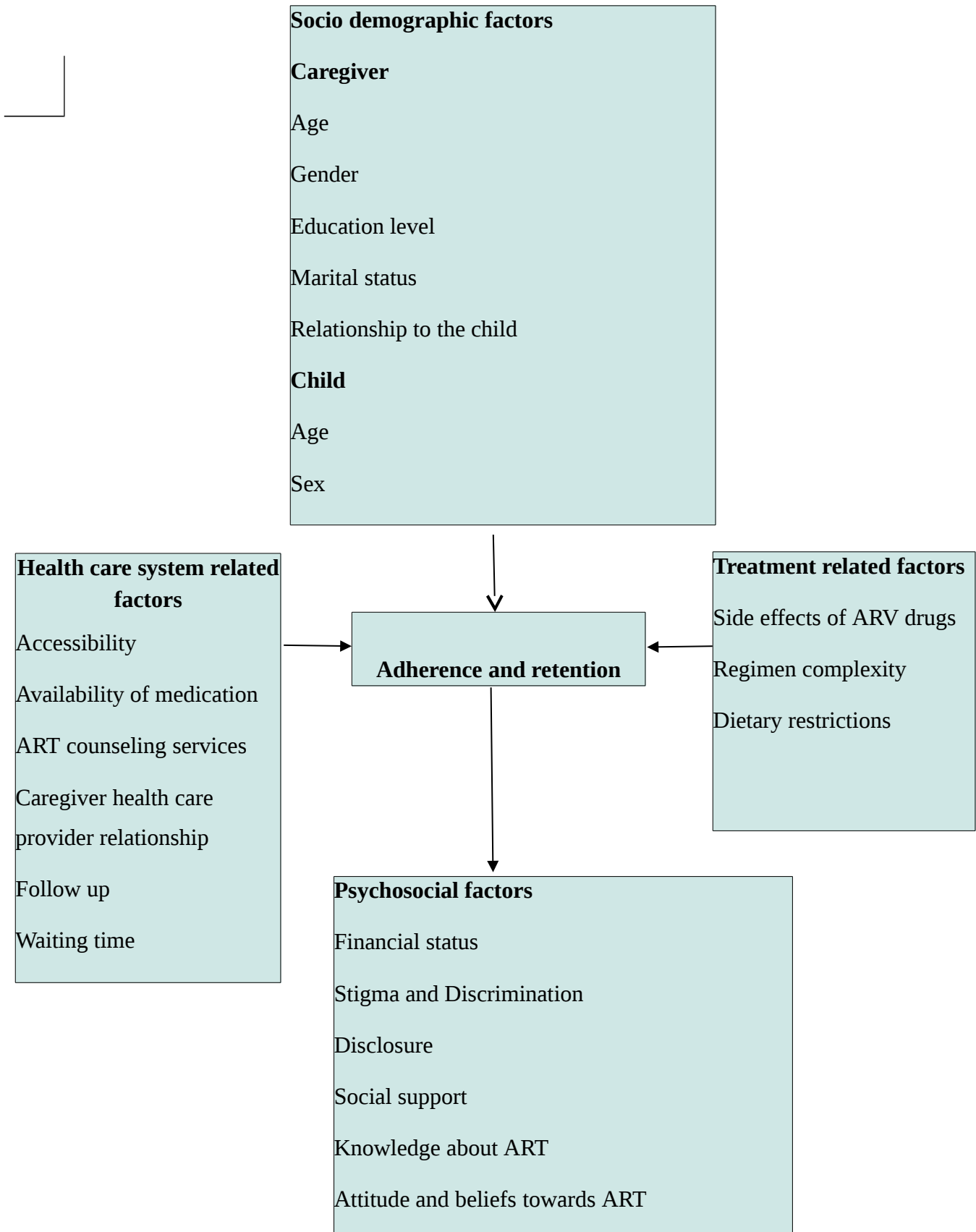
Also this research critically studies an issue that faces every child infected with HIV/AIDS in every society in the world over including ours as well, with the aim of providing viable information for sustaining adherence treatment plans.

And finally, this work would serve as reference material for future researchers who intend to carry out researches that are related to this one in particular. A lot of information can be sourced from this work and they can be further improved on as well.

1.6 THE CONCEPTUAL FRAMEWORK

The conceptual framework below shows the independent and dependent variables under the study. The independent variables with socio – demographic factors, psychosocial factors, Treatment related factors and Health care system related factors have direct influence on the dependent variable which is Adherence to ART therapy.

Figure 1: Conceptual framework



CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

The literature review covered reports within the context of HIV/AIDS, ART, adherence to ART and caregiver-related factors affecting adherence to pediatric ART. Reviewed documents were obtained from websites, journals articles, WHO publications and EMOH publications. The literature review covered the period from 2008-2015.

2.1 Adherence and antiretroviral therapy

In order to suppress the viral load to undetectable levels (< 50 copies / ml), the rates of adherence have to be above 95% but even with these adherence levels, some patients display detectable HIV RNA (*Sharon et al., 2012*). A study in Brazil (*Porto Alegre*) evaluated the effectiveness of treatment at different degrees of adherence in children and concluded that 59.5% of the children were adherent (*Ferreira et al, 2013*). Establishing and maintaining adherence to medication is a difficult goal for a child with HIV even when treatment regime is simple and the patient is clearly symptomatic. ARV treatment for children requires collaboration between the child and caregiver in terms of commitment of caregiver and cooperation of the child. Successfully treating a child requires the commitment and involvement of a responsible caregiver. In a study to assess pediatric adherence to ART in Toto, West Africa, only 58% caregivers declared perfect adherence (*Julie et al., 2008*).

2.2 Measurement of adherence

One major barrier to measuring and ultimately improve adherence is lack of any gold standard for measuring adherence. A number of measuring strategies exist including pill count, electronic monitors, diaries and report questionnaire. Each of these methods has limitations and can provide different estimate of adherence. Adherence measurements in HIV patients in recent research have suggested that use of multiple measures will be of greater benefit than continue search for single defining adherence measure. It is apparent that use of drug plasma concentration is the most accurate and objective way to assess adherence. However the use of this method has logistic and cost implications.

2.3 Art uptake among children in Uganda.

Although access to ART has markedly improved in developing countries, children are lagging behind adults. For instance, out of 800,000 people on ART in Uganda only about 41,520 (22 %) are children (*UNAIDS, 2014*). It was estimated that 100,701 children are eligible for starting ART but only 44 % access it , retention on ART at 12 months after initiation was 83% in September 2013; higher for adults at 84% compared to children at 73% (*UNAIDS 2014*).

2.4 Care giver factors associated with adherence to antiretroviral therapy

Adherence outcomes are influenced by several caregiver characteristics. A child's adherence to ART is unequivocally influenced by caregivers and family function, which may change over period. The caregiver physically administers the medicine to the child. While this physical role diminishes as the child grows older, the need for caregiver and family support remains critical at every age. Therefore the following paragraphs provide evidence-based look at the caregiver factors associated with ART adherence among children and review how key caregiver characteristics, might influence promotion of ART adherence among children.

2.5.1 Socio demographic factors

2.5.1.1 Caregiver

Studies have found that, with the exception of the most elderly, pediatric adherence to ART increases with caregiver age (*Jones et al., 2009*). Some studies revealed that caregivers of young age were significantly associated with low level of pediatric adherence to ART (*Beer et al 2012: Fumaz et al 2008:*). In two studies associated with ART, adherence and retention showed a positive correlation with younger age of caregiver (*Nakashima et al 2009*). But, other studies did not support any association of pediatric adherence to ART with age of caregiver (*Aragonés et al 2011:Sharma, et al.,2013*)

Studies have also demonstrated variable results on the association of caregiver sex with pediatric adherence to ART behavior. Though some studies have found that caregiver of female gender is significantly associated with low level of adherence and caregiver of male gender correlates with better adherence (*Fumaz et al 2008:*), other studies found that caregiver of female gender was associated with higher rates of pharmacy adherence (*Rougemont, et al 2009:*). Nevertheless, other studies did not support any association of pediatric adherence to ART with gender of caregiver (*Aragonés et al 2011*).

Caregiver's marital status has a profound effect on pediatric ART adherence, a cross sectional study by *Makhema, et al. (2013)* on caregivers in Botswana revealed that married couples were more likely to have adherent children than the divorced or separated couples. A study done in Nigeria showed that children enrolled on ART whose parents were single, were significantly associated with non-adherence to ART (*Uzuchukwu et al 2011:*) . Children whose caregivers were not living alone and had partners were associated with higher rates of adherence to ART therapy (*Motashari et al., 2008*).

The relationship between the caregiver and the child may have a profound influence on adherence. Giving medication is an interactive process that is shaped by the child's behavior and the caregiver's expectations. Caregivers who are biological parents of HIV-positive children often share their diagnosis and confront challenges associated with their own illness and its comorbidities. Thus, they may be physically fatigued or debilitated (*Brigido, 2012*). In these cases, treatment can become a reminder of the parents' guilt about their role in their child's acquisition of infection, which is yet another challenge to adherence. Conversely, a Romanian study found that out that non-biological guardian were associated with awful adherence. A biological guardian might may have a stronger emotional attachment with the child and be more motivated to promote good adherence compared with a non-biologic guardian (*Pontali, 2015*).

Caregiver low levels of general education and poorer literacy impacts negatively on some children's ability to adhere to ART therapy (*Moralez, et al., 2009*) while a higher level of education has a positive impact (*Catz, et al, 2009*). A Thailand study of caregivers to children enrolled on ART showed pediatric non adherence to ART therapy was associated with caregiver completing secondary school (*Hansana, 2013*). However, another study conducted by *Cauldbeck et al (2009)* showed no association between caregiver literacy with pediatric adherence to ART therapy. An Indian study found a significant association between non-adherence and poor caregiver levels of education, *Pothak, (2014)*.

2.5.1.2 Children

Children below five years of age are over two times more likely to be non-adherent. This could be because of their complete dependence on an adult caregiver who may be preoccupied with other duties, and the difficulty in administering drugs to this age group (*Nakashima et al 2009*). The changing abilities and needs of children, psycho social, physical and emotional, create complex challenges over period. For drug administration, children depend entirely on their caregivers, including re-dosing after vomiting, which is common at this age. Challenges for children typically include independence and

medication refusal. School going children often develop the ability to understand concepts of illness and the need for treatment, though often not aware of their illness. These children might wonder why they are taking medicines every day when their peers are not (*Battles HB, et al, 2013*).

Several studies have found male sex to be significantly associated with adherence outcomes. In a large multisite study from Nigeria, male children had a 20% higher rate of non adherence (*Goldwin et al., 2008*). In western Kenya, the rate of non-adherence among male children was 28 % but 23.8% among female (*Metros et al., 2008*). However these generalizations are not universal. In China, which has a concentrated rather than a generalized epidemic, the female children were more likely to miss their treatment doses during the first 6 months of ART initiation (*Ying Liu, 2013*).

2.5.2 Psychosocial factors

Literature reveals that children whose caregivers have higher incomes have less difficulty with adherence to ART therapy (*Maridadi, 2008*). In the Futures II study, which surveyed 824 caregivers of Thailand HIV positive children, more than half of the respondents reported experiencing some difficulty in meeting the cost of daily living (*Grierson, 2010*). Financial trouble prevents caregivers of children from collecting medication on time, sometimes patients are forced to choose between paying for transportation to the ART facility and using the money for food (*Brigido, et al., 2008*). Studies in Uganda reported that transportation costs are considered serious obstacles to taking ART (*Horne, et al., 2008*). This has implications not only for day-to-day adherence but also losses to follow up.

A Kenyan study conducted on caregivers to children enrolled on ART revealed stigma to be one of the major barriers to pediatric adherence to ART. Even though ART is to be taken life-long once started, significant social stigma may partially or completely disrupt the child's drug adherence levels. The studied caregivers described stigma in different ways: shyness, fear of being laughed at with their children, fear of being embarrassed or that others would know the status of their children (*Valdez et al., 2008*). A study done in five African countries (Lesotho, Malawi, South Africa, Swaziland and Tanzania) found that stigma interfered with adherence to ART, perceived stigma was correlated with missed ART doses (*Dlamini, et al., 2009*).

A study conducted by *Nachega, (2009)* revealed that children whose caregivers had not disclosed the child's serostatus to any other person had worse adherence. Another study by Bosch also showed that children whose HIV status was not disclosed had lower adherence levels. Similarly, Kaharuza's study

revealed that complete disclosure of HIV status by caregivers to children and strong parental relationships were related to good adherence. Disclosure is related to good or improved adherence to ART medications and influences children's participation in healthcare decision-making. It also enables children to understand HIV infection and make sense of their disease related experiences as well as the importance of adherence. Different studies show that disclosure is associated with higher self-esteem, fewer symptoms of depression, improved adherence and higher CD4 counts, seek social support and have improved coping skills (*Ickovics et al., 2013*).

A recent study conducted with caregivers in South Africa reported a 26% disclosure rate among children aged above than six years (*Moodley et al., 2010*), although all caregivers recognized the importance of pediatric disclosure. Disclosure of HIV or AIDS diagnosis to infected children and youth is indeed a complex process that presents a complex challenge to both families and health care providers. The HIV-infected parents are reluctant to disclose because they fear its impact on the child's psychological and emotional health, it may lead to depression in the child, the child cannot keep a secret, the child will suffer from social rejection and stigma (*Wiener et al., 2009*).

Children whose caregivers were living alone and lacked support were associated with an increase in sub-optimal adherence *Williams et al, (2014)*. High adherence levels were also observed in a recent study of children infected with HIV/AIDS from Uganda in which caregivers received individual and group sessions on HIV prevention, care and treatment, family members received education, clients had support from a "medicine companion" and health workers delivered medications at home (*Weidle PJ et al., 2011*). A recent study conducted in South Africa revealed that belonging to a support group, is associated with good adherence. Support groups play a big role in educating caregivers on the importance of adherence to ART treatments hence monitoring the adherence behaviours of the children (*Mills et al., 2011*).

Available evidence suggests that a good level of understanding about ART and awareness of the consequences of non-adherence are associated with good adherence (*Fumaz et al 2008*). A South African study conducted among urban pediatric caregivers, found that lack of knowledge regarding ART was associated with non-adherence to ART. In the absence of adequate information about HIV and ART, when children felt better, they were discontinued from ART, thinking that their HIV/AIDS had been cured (*Murray et al 2009*).

Patient beliefs about illness and the efficacy of the treatment affect adherence behavior. A belief in the efficacy of ART cultivates faith in the treatment regime (*Mills et al. 2011*), caregivers who do not accept their child's illness are two times less likely to be concerned about adherence. A French study found that caregivers who acknowledge the child's illness would be more likely to internalize the information received from the health care providers, hence develop a stronger motivation to fight for the child's life (*Wenger, et al, 2009*). In another cross sectional study of South African mothers, adherence practices were influenced negatively by children adopting the poor attitudes about medications from their mothers (*Dahab et al., 2008*).

A caregiver's beliefs about the child's illness and the effectiveness of medication are predictive of adherence. The caregiver's belief that ART is effective, prolongs life (*Harpham, et al., 2008*), and a recognition that poor adherence may result in viral resistance and treatment failure (*Wenger et al, 2009*) all impact favorably upon a child's ability to adhere. Conversely, a belief that ART may in fact cause harm adversely affects adherence to ART among children (*Johnston, et al, 2008*). Caregiver's beliefs that medications need to be taken with food leads children avoiding taking medications whenever food is unavailable hence interfering with adherence. (*Dahab et al., 2008*).

2.5.3 Health care system related factors

Structural factors not directly related to patient or medications can also influence adherence. Some researchers have even contended that these could be the most important barriers to ART adherence in resource limited settings.

Accessibility to antiretroviral medications and health care facilities for diagnosis and treatment of HIV/AIDS is associated with non-adherence to ART. Distance to clinic and transportation are major barriers to retention in care in a wide variety of settings in Africa and Asia (*Furtado, 2012*). In rural Uganda, among 111 children lost to follow-up, the most common reasons for absence were lack of transportation in 50% and excessive distance in 42% (*Martin, 2010*). A study conducted in rural Malawi, revealed there was lack of adequate health facilities or services near the patient's homes, hence necessitated traveling to distant health units to access treatment therefore failure to raise transport increased chances of non-adherence and missing of drugs and that 35% of children who were lost and traced cited the high cost of transport to the clinic as the reason for absence, (*Makombe, 2010*). In India, among 106 caregivers who failed to return for 3 or more months, 20% cited distance and lack of transportation (*Mathur, 2010*).

There is limited availability of antiretroviral medications for management of HIV/AIDS. In addition, some dispensing pharmacies will only dispense one month's medication at a time. Not all pharmacies are able to dispense anti-HIV drugs; as a result, some children attend their local pharmacy for most prescription medicine and a specific pharmacy for their anti-HIV therapy (*Grierson, 2010*). In developing countries the story is very worrying as lengthy waits in a few hospitals that do not have extended hours may also impede adherence (*Grierson, 2010*).

Availability of counseling services and social, economic, or psychological support for caregivers and their children can influence adherence positively or negatively. It is essential that all caregivers should demonstrate an understanding of the importance of adherence to ART before starting the treatment. Caregivers must be given complete information that ART is a lifelong treatment. Empowering caregivers and assessing their understanding might be regarded as time consuming and labour intensive, but it is appropriate in order to achieve the expected results (*Mathur, 2010*). Giving a prescription at the first visit without proper adherence counselling, amounts to gross negligence. However, this is a common practice in many places (*Maridadi et al., 2010*).

Effective interactions between patients and health care practitioners have been shown to be important in patients' acceptance and continuation of treatment (*Bultman, 2008*). A good patient-health-care provider relationship may be an important motivating factor for taking and adhering to complex combination drug therapies. On the other hand, factors that have been identified as strengthening patient-health-care provider relationships include perceptions of health-care provider competence, communication quality and clarity, compassion, willingness to include patients in treatment decisions, adequacy of referrals, and convenience of visiting the doctor. (*Braun et al, 2011*). Conversely, frustration for health-care providers is associated with lack of patient adherence to treatment, miscommunication and missed appointments. In light of these problems, it is heartening to find that initiatives are underway to encourage health-care providers to work with patients as "partners" in care and to involve representatives from the entire HIV community (*Martin, 2010*).

Follow – up has been shown to be associated with adherence among pediatrics. A study conducted by *Chalker, et al (2008)* involving 510 patients starting ART in four treatment programs in Africa and Asia, with at least 12 months of follow up, found out that caregivers were more motivated to promote good adherence if initiated under a follow up program. Caregivers are more likely to adhere to the strict ART regimen if followed up by healthcare providers. (*Williams et al, 2014*).

Caregivers are more likely to miss appointments if they are not attended to within a reasonable time *Maokisa (2012)*. A study conducted by *Martin (2010)*, revealed that caregivers who experienced long waiting hours were discouraged from going to the clinics for their monthly reviews and refill. Waiting for long hours were stressful hence the problem of long waiting times was cited as a major challenge to adherence. In Botswana, most respondents reported that they spent around four hours at the clinic. Nearly half of the respondents spent even more than that, with the longest wait being 12 hours, as caregivers may miss one working day per month in order to get ART therapy refill which can be a problem for some caregivers whose employers are not aware of the sero status of their children or do not support their need for care (*Maokisa, 2012*).

2.5.4 Treatment related factors

Characteristics of the commercially available drug formulations such regimen complexity, adverse effects and dietary restrictions can significantly affect adherence. The above-mentioned medication-related factors are crucial in determining children's adherence to ART.

Side effects are relatively a less common reason for disengagement from care. In the Themba Lethu Clinic in Johannesburg, among 70 children who were lost to follow-up, only 1.4% cited side effects as a reason for failure to return to clinic and in a later study at the same site, only 4.1% reported toxicity as a reason for absence (*Rubel et al, 2011*). Drug hypersensitivity is far more common in patients with HIV and regimen associated toxicity is a common predictor of, and reason for, non-adherence across many studies (*Ickovics & Meisler, 1997*). In another clinic in Zambia, 2.9% of 90 lost children reported toxicity as a reason for absence (*Rosen et al, 2010*).

The complicated regimen to be followed, such as the need for daily administration, drug interactions, frequency of dosing, dosage, and pill burden or amount of liquid influence child's adherence to therapy. Intrusive regimens, ones that require blood monitoring or physical therapy have poorer rates of adherence (*Mills et al, 2008*). Treatments for HIV are especially challenging, as they require multidrug regimen compliance yet failure to comply can result in new drug resistant strains, producing individual and society wide threats. The physical aspects of a particular medication, taste, size, formulation etc, associated with lifestyle changes may also affect a child's ability to be adherent (*Crespo-Fierro, 2009*).

Dietary restrictions have been shown to be significantly associated with adherence. Intrusive regimens, that require dietary changes, have poorer rates of adherence (*Mills et al, 2008*). Dietary conditions often

require adjustments in lifestyle. Children can find their meal schedule compromised by ART drugs that require dosing on a fasted stomach. This can be particularly difficult if, family or friends are unaware of the patient's HIV status (*Grieson, et al., 2010*).

2.6 Conclusion

Adherence outcomes in children are more dynamic than in adults. While much progress has been made in treating HIV-infected children in recent years, especially in developing countries, unacceptably high rates of treatment failure and drug resistance have been observed among children. Moreover, many HIV-infected children are surviving to adolescence and engaging in sexual relationships, which create a public health risk of transmitted resistance. Combined efforts in clinical care and research are required to help this vulnerable population.

CHAPTER THREE

METHODOLOGY

3.0 Introduction

This chapter describes the methodology of the study which includes the research design, the area of study, sources of data, the study population, sampling procedures, sample size calculation, study variables, data collection techniques, data collection tool, plan for data analysis, quality control issues, plan for dissemination, study limitations and ethical considerations.

3.1 Study design.

This research study utilized a descriptive cross-sectional study employing quantitative methods of data collection. A cross – sectional design was used because data was obtained at one specific point in time and aimed to provide data on the entire population under study. The researcher intended to present facts concerning the nature and the status of the situation, as it existed at a time of the study and described the present conditions and events based on impressions of the respondents of the research. The design offered a quick and easy way to quickly a mass data and was relatively inexpensive and took up little time to conduct. Assessment of outcomes for the entire population was also done with little trouble, as the sample was a near perfect snapshot of the whole.

3.2 The area of study

The study was conducted at Kisugu Health Centre III at the HIV/AIDS clinic among caregivers of HIV infected children attending ART clinic. Kisugu Health Centre III a public health facility run by KCCA and located in Kisugu Parish, Makindye east constituency, found in Kampala District, the capital city of Uganda. Kisugu Health Unit has a length of 0.15 kilometers. The coordinates of Kisugu health center III are: Latitude: 0°18'24.12" and Longitude: 32°36'41.76". Kisugu health center III a busy health facility which attracts a significant number of caregivers to HIV infected children from different parts of Makindye East division of Kampala. This helped the researcher to be able to obtain data from a group of caregivers of HIV infected children from a diverse setting and background.

3.3 Sources of data

The major sources of data were the selected caregivers whose children were attending the antiretroviral therapy clinic at Kisugu Health Centre III for primary data, internet literature for previous studies, journals and books for secondary data.

3.4 Study population

The population under this research study comprised of all caregivers whose children were attending the antiretroviral therapy clinic at Kisugu Health Centre III during the time of the study.

3.5 Selection criteria

3.5.1 Inclusion criteria

Caregivers considered were those that reported an understanding of the 24 hour-a day regimen and who were responsible for administering at least 50% of the doses of medication to the children attending Kisugu Health Centre III antiretroviral therapy clinic and consented to participate in the study.

3.5.2 Exclusion criteria.

The following categories of caregivers were not included in the study: Caregivers not responsible for administering treatment, sick caregivers who were not able to participate, those who were very busy at the time of data collection and the ones who did not consent.

3.6 Sample size determination

Using Kish and Leslie's formula of sample size determination. The sample size was calculated as follows.

$$N = Z^2PQ / e^2$$

Where;

N is the appropriate required sample size.

Z is the standard deviation corresponding to 95% and confidence interval of 1.96.

P is the Proportion of ART adherence among children, was estimated at 85.7% (0.857) South Nigeria (*white et al, 2008*).

e is the standard error or level of significance (taken to be 5% [0.05]).

Q is $1 - p$,

Thus,

$$N = \frac{(1.96)^2 (0.857) (1 - 0.857)}{(0.05)^2} = 188.34$$

N is approximately 188.

Therefore, the sample for this study was be composed of **188** respondents

3.7 Sampling technique

The researcher used simple random sampling in the selection of the primary caregivers to participate in the study so as all primary caregivers were given an equal opportunity to participate in the study.

3.7 Sampling procedures

The study used probability sampling where simple random sampling was used to select the caregivers who had children attending the HIV/AIDS clinic. In this case, the caregivers who brought their children to the HIV/AIDS clinic during the time of the study were randomly selected with an equal opportunity and requested to participate in the study. The researcher proceeded and gave potential respondents who met the study criterion an opportunity to pick papers from a box and anybody who picked a paper with the word written YES on it, was requested to participate. This continued until the desired total number of respondents was achieved. In this case, each member of the population would have an equal chance of being selected. Simple random sampling allowed the researcher to draw externally valid conclusions about the entire population based on the sample hence suits the study.

3.8 Study variables

3.8.1 Dependent variable

The dependent variable of this research study was adherence and retention among children infected with HIV/AIDS attending Kisugu Health Centre III.

3.8.2 Independent variables

The study was guided by four independent variables which included;

Socio demographic factors;

Level of education, age, gender, marital status, relationship to the child and age of the child and gender of the child.

Psycho social factors;

Financial status, stigma and discrimination, disclosure, social support, knowledge about ART, attitude and beliefs towards ART.

ART Treatment related factors;

Side effects of ARV drugs, dietary restrictions, and treatment regimen complexity.

Health care system related factors;

Accessibility, availability of ART medication, caregiver health care provider relationship, and availability of counseling services for ART.

3.9 Data collection tool

Data was collected using a structured interview administered questionnaires. Originally written in English, the interview-guide was translated into the local language Luganda and double checked by three independent translators. The questionnaires helped all caregivers to children on ART to respond to the same set of questions in a pre determined order to collect subjective and objective data. The questionnaire contained questions on socio demographic factors, psycho – social factors, health care system related factors and treatment related factors associated with adherence among HIV/AIDS infected children.

3.10 Data collection techniques and data management

3.10.1 Pre – visiting

A visit to the study area was made before data collection. This helped the researcher to get prior knowledge and further insight about the study area, the leadership protocols necessary, the target respondents and informal permission to go to the study area.

3.10.2 Pre – testing

The research tool (questionnaire) was tried and piloted on 10 respondents at Kiswa health centre Bugolobi, Kampala in order to identify problems with the data collection process and areas of improvement. This was a health center with similar characteristics to that of Kisugu Health Center III where the study was based. Pilot testing ensured credibility, accuracy, validity and reliability of the questions. Where necessary this resulted in adjustments in the tools so that some questions were deleted, rephrased, eliminated or even added.

3.10.3 Training of research assistants

The researcher trained the research assistants so as to help in the data collection process. The assistant was oriented on how to use the data collection tool and observe all necessary procedures.

3.10.4 Editing

Editing of the questionnaire was done in the field immediately after each interview of each respondent before proceeding to the next respondent. This involved checking for completeness of the responses for each question. It also required checking that each question had an appropriate and complete response; and a response to the appropriate question. This was done to save time and avoid call backs to the respondents.

3.10.5 Coding

Coding means assigning a numerical number to a response. A coding frame was made for each question which had a set of options to tick(check). This facilitated data entry and analysis. The questionnaire was pre – coded. Where need be post coding was done after field for other specific responses and elaborate responses which the researcher had not predicted.

3.10.6 Data entry

After field data collection, data entry followed. This required construction of a template into which data was exported from the questionnaires. The template was constructed from Microsoft Excel, a computer software.

3.10.7 Data storage

Data storage was critical for quality of data, hence boxes for storage of tools were available. One for the empty questionnaires, the second for the filled questionnaires until the sample size was reached. Both boxes were strictly kept by the researcher. Upon entry to capture data in the template the entered questionnaires were kept in the third box until data cleaning. The computer template and draft reports were stored on soft copies all of which had passwords known by the researcher only. This was done to avoid alterations by unauthorized people. Variety of soft copies provided a backup, in case of corrupted documentation

3.10.8 Data cleaning

Data cleaning was done for entered data to check for errors and omissions traceable in the field data tools. This ensured that quality data was presented and analyzed.

3.10.9 Data collection procedure

Data was collected by interviews using a researcher structured questionnaire. All caregivers bringing children to the HIV/AIDS clinic voluntarily completed the survey if they so choose. The researcher was responsible for collecting the information and ensured that it was kept in a safe and confidential place.

3.11 Plan for data analysis and presentation

Descriptive statistics were used in data analysis and allowed the researcher to organize data in ways that gave meaning and facilitated insight. The analysis of the data collected was done by means of computer software Statistical Package for Social Sciences (SPSS) Version 16.0 and Microsoft Excel 2010 and descriptive statistics summarized the data into frequencies and percentages. The analytical statistics inferences were employed to show the level of association between the variables under the

research study. Presentation of the study findings was in form of charts, graphs, figures and tables in order to provide summarized and simplified picture about the outcome of this research study.

3.12 Quality control issues

At the end of data collection day, the tools were checked for accuracy and consistency. The data that was collected was kept in a cabinet under lock and key to protect the study respondents and to ensure confidentiality of data collected. Data was coded, cleaned and double entered. At the conclusion of this research study, all completed questionnaires were safely kept for a year after which will be shredded and destroyed.

3.13 Plan for dissemination of results

The copies of the dissertation were submitted to International Health Sciences University (IHSU) and the local authorities at Kisugu Health Centre III.

3.14 Limitations of the study

The limitations to the research study were as follows;

Low transparency among respondents in answering the questions

Communication concerns such as language barrier or questions misunderstanding

Poor time management in case where some respondents took a lot of time to complete the questionnaire

3.15 Ethical considerations.

An ethical clearance was obtained before conducting this research from Kisugu Health Center III. The in charge was asked permission using a formal letter from the International Health Sciences University research committee. Respondents were provided with clear information and asked if they were willing to participate or not and this ensured the right of self-determination and autonomy. Only those who were willing to participate were involved. Written informed consent was obtained from clients who participated in the study. Confidentiality of responses was maintained throughout the research process through anonymity. Personal privacy and cultural norms were respected properly. The data obtained was treated privately with no name tag on it. All completed questionnaires were stored in a locked and secured area. After the survey, responses were coded and after 1 year all original surveys were shredded and destroyed.

**CHAPTER FOUR:
DATA PRESENTATION AND ANALYSIS**

4.0 Introduction

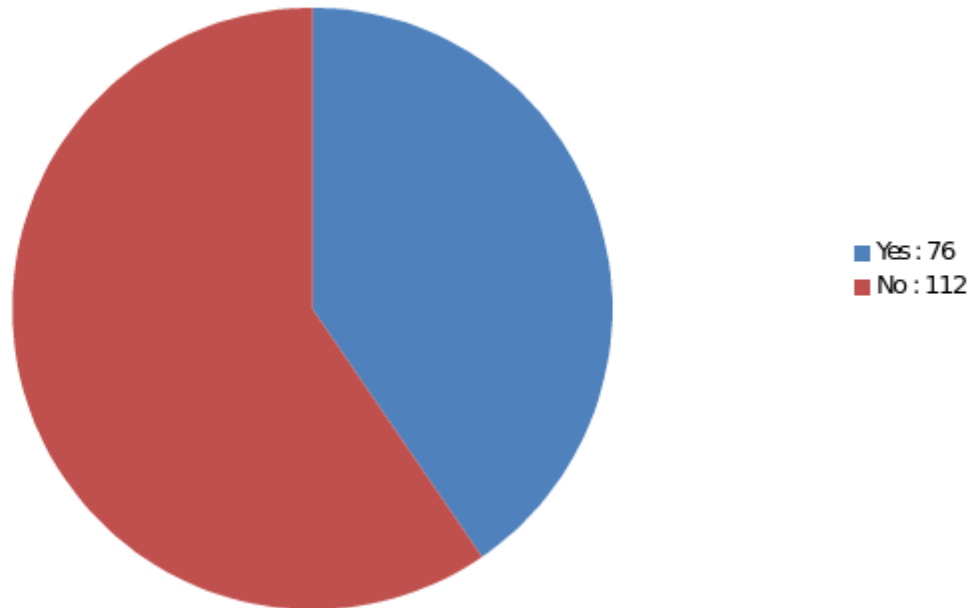
This chapter presents the results of the findings from the study and the analysis of these results. The results are presented in four sections as socio demographic factors, psycho social factors, treatment related factors and health-care system related factors of the study population and in accordance with the specific objectives of the study using percentages, tables, graphs and charts.

4.1 Prevalence of Adherence

The final sample consisted of 188 caregivers. 40.4% (76) of the caregivers admitted to having missed a administered a dose of ART treatment the previous week preceding the study. This puts the estimated rate of non-adherence at 40.4%. The rate of adherence at Kisugu Health Centre III Hospital, therefore, was 59.6 %(112).

Figure 2: Showing the prevalence of adherence

missed dose of medication in the last week preceding the study



4.1.1 Caregiver reasons for missing medications

Among caregivers who missed giving medications to their child in the previous week, the reasons for missing medications were forgetfulness (35.6%), being busy (22.3%), inter current illness (16%), child refused (12.8%), did not refill (8.5%), feeling better (4.8%).

Table 1: Showing caregiver reasons for missing at-least one dose of medication

Caregiver reasons for missing medication	Frequency	Percentage
Forgetfulness	67	35.6%
Being busy	42	22.3%
Inter current illness	30	16%
Child refused	24	12.8%
Did not refill	16	8.5%
Feeling better	9	4.8%
TOTAL	188	100

Source: Primary data

4.2 Association of Adherence to Socio-Demographic factors of the Caregiver and Child.

Majority of the caregivers 63(33.5%) were between 31 – 40 years, followed by those in the 21 - 30 age brackets 35[18.6%]. The lowest percentages of adherence were observed in caregivers 61 and above years of age 10[47.6%]. There was no statistical significance association between age of the primary caregiver and adherence ($P < 0.05$ [0.419]).

Majority 115(61.2%) of the respondents were female. Worth noting was that 64[55.7%] of the female compared to 48[65.8%] of male caregivers' their children did adhere to the ART treatment. However the variable gender of the caregiver" showed no significant statistical importance to adherence. ($P < 0.05$)[0.171].

Regarding level of education 9[4.8%] of the caregivers had no formal education, 39(20.7%) had primary education, 68[36.2%] had attained secondary level of education, 72[38.3%] had tertiary level. There was a statistical significant association between the variables caregiver's education level and

adherence with $P > 0.05$ [0.004] in bivariate analysis.

It was evident that 89(47.3%) of the caregivers were married, 41(21.8%) were single they were either widows/widowers or were unmarried and 58(30.9%) were divorced. Worth noting was that a higher percentage 56[62.9%] children of married caregivers were adherent as compared to 24(58.5%) children of single caregivers, and 32[55.2%] children of divorced caregivers. However caregiver's marital status showed no statistical significant association to adherence ($P > 0.05$ [0.346]). (Table 2).

Majority 152[80.9%] of the children were being cared for by their biological parents, 29[15.4%] by their guardians while 7[3.7%] were under foster care. There was a statistically significant association between the variables caregiver's relationship to the child and adherence $P > 0.05$ [0.000]. A higher rate 106[69.7%] of adherence was observed among biological parent caregivers as compared to guardians 5[17.2%] and foster parents 1[14.3%].

More than half 128 (68.1%) of the children were female and 60 (31.9%) male. Though the number of female children was more than that of male children, There were higher adherence levels among male children 40[66.7%] compared to female children 72[56.2%]. There was no statistical significant association between adherence and gender of the child ($P < 0.05$ [0.177]) (Table 2).

Slightly more than half of the children 96(51.1%) were over 5 years whereas 92(48.9%) were under 5 years. Children under 5 years of age recorded a higher percentage of adherence 61[66.3%] as compared to 51[53.1%] of children 6 years and above. Age of the child had no association with adherence. ($P < 0.05$ [0.066]).

Table 2: Association of Adherence to Socio-Demographic factors of the Caregiver and Child.

Independent variable	Frequency	Adherent	Non Adherent	Statistical test
Age of the caregiver				
20 and below	25[13.3%]	14[56.0%]	11[44.0%]	P<0.05[0.419] Not significant
21 - 30	35[18.6%]	22[62.9%]	13[37.1%]	
31 - 40	63(33.5%)	42[66.7%]	21[33.3%]	
41 - 50	22[11.7%]	10[45.5%]	12[54.5%]	
51 - 60	22[11.7%]	14[63.6%]	8[36.4%]	
61 and above	21[11.2%]	10[47.6%]	11[52.4%]	
Gender of the caregiver				P<0.05[0 .171] Not significant
Male	73(38.8%)	48[65.8%]	25[34.2%]	
Female	115(61.2%)	64[55.7%]	51[44.3%]	
Education				P>0.05[0.004] Significant
No formal education	9[4.8%]	3[33.3%]	6[66.7%]	
Primary level	39(20.7%)	15[38.5%]	24[61.5%]	
Secondary level	68[36.2%]	46[67.6%]	22[32.4%]	
Tertiary	72[38.3%]	48[66.7%]	24[33.3%]	
Marital status				P<0.05[0 .346] Not significant
Married	89(47.3%)	56[62.9%]	33[37.1%]	
Single	41(21.8%)	24(58.5%)	17(41.5%)	
Divorced	58(30.9%)	32[55.2%]	26[44.8%]	
Relationship to child				P>0.05[0 .000] Significant
Parent	152[80.9%]	106[69.7%]	46[30.3%]	
Guardian	29[15.4%]	5[17.2%]	24[82.8%]	
Foster care	7[3.7%]	1[14.3%]	6[85.7%]	
Age of the child				P<0.05[0.066] Not significant
0 – 5 years	92(48.9%)	61[66.3%]	31[33.7%]	
6 – 12 years	96(51.1%)	51[53.1%]	45[46.9%]	
Sex of the child				P<0.05[0 .177] Not significant
Male	60(31.9%)	40[66.7%]	20[33.3%]	
Female	128(68.1%)	72[56.2%]	56[43.8%]	

Source: Primary data

4.4 Association of Adherence to the Psycho social-factors of The Caregivers

Findings from the study indicated that majority 170(90.4%) of the caregivers were employed (formal/informal) while the minority 18 (9.6%) were unemployed. Out of 170(90.4%) who were employed, 67(35.6) had full time formal employment, 74(39.4%) had part time formal employment and only 29(15.4%) were self-employed. Caregiver’s Financial status was not statistically associated with adherence with P<0.05[0.509]. It was however, noted that a lower proportion of those in employment adhered to ART.

Support received by the caregivers had significant association with adherence outcomes (p>0.05)

[0.043]. More than half, 134[71.3%] of the caregivers were receiving support and the rest of the respondents 54[28.7%] were not receiving any form of social support. Out of 134[71.3%] caregivers, 77(57.5%) reported that they received support inform of counseling, 20(14.9%) materialistic support, while 9(6.7%) received support inform of food and 28(20.9%) received support in other various forms.

Table 4: The different forms support received by the caregivers

Type of support	Frequency	Percentage
Emotional support	77	57.5
Instrumental support	20	14.9
Appraisal support	9	6.7
Informational support	28	20.9
Total	134	100

Source: Primary data

On disclosure of child's status, only 88(46.8%) of the caregivers were willing to disclose the child's status and slightly more than half 100(53.2%) caregivers were unwilling to disclose the child's status. Nonetheless disclosure of child's status had no significant association with adherence outcomes ($p>0.05$) [0.310].

Majority 150[79.8%] of the caregivers reported that they had ever encountered secondary stigma and discrimination in the community as a result of providing care to infected children and only 38[20.2%] of the caregivers reported that they had never encountered secondary stigma and discrimination. There was no significant statistical association with adherence outcomes $P<0.05$ [0.894].

On role of ART, 83[44.1%] of the caregivers were aware that ARV's reduced the progression of HIV, 64(34%) either believed it was a cure, 22[11.7%] believed they were for pain relief and 19(10.1%) had no idea of the role played by ARV's. There was no significant statistical association with adherence outcomes $P<0.005$ [0.120].

It was evident that majority 171[91.0%] of the care-givers had ever discontinued their children from ART treatment once the symptoms of HIV disease improved or because of other specific reasons. Most of the respondents 102[59.6%] who had ever discontinued their children from ART treatment reported

that their children were adherent to their treatment. However there was no significant statistical association with adherence outcomes $P < 0.05$ [0.948].

More than half 128(68.1%) of the caregivers had a belief that ART is effective and the others 60(31.9%) believed ART was not effective. There was no significant statistical association with the adherence outcomes $P < 0.05$ [0.814]. Majority 130(69.1%) believed ART could improve the quality of life of the child whereas 58(30.9%) believed that ART could not improve the quality of life of the child. A higher percentage 76[58.5%] who believed that ART could improve the quality of life of their children were adherent to the treatment as compared to 36[62.1%] who did not agree. Nonetheless there was no significant statistical association with the adherence outcomes $P < 0.05$ [0.644].

Table 3: Association of Adherence to the Psychosocial-factors of The Caregivers

Independent variable	Frequency	Non adherent	Adherent	Statistical test
Financial status				
Full time employment	67(35.6%)	40[59.7%]	27[40.3%]	P<0.05[0.509]
Part time employment	74(39.4%)	48[64.9%]	26[35.1%]	Not significant
Self employed	29(15.4%)	14[48.3%]	15[51.7%]	
Unemployed	18(9.6%)	10[55.6%]	8[44.4%]	
Receiving Social Support				
Yes	134[71.3%]	86[64.2%]	48[35.8%]	P>0.05[0.043]
No	54[28.7%]	26[48.1%]	28[51.9%]	Significant
Disclosure of the child's status.				
Willing	88(46.8%)	49[55.7%]	39[44.3%]	P<0.05[0.310]
Not willing	100(53.2%)	63[63.0%]	37[37.0%]	Not significant
Secondary stigma & discrimination				
Yes	150[79.8%]	89[59.3%]	61[40.7%]	P<0.05[0.894]
No	38[20.2%]	23[60.5%]	15[39.5%]	Not significant
Role of ART				
Reducing progression of HIV	83[44.1%]	54[65.1%]	29[34.9%]	P<0.005[0.120]
Curing HIV	64[34.0%]	38[59.4%]	26[40.6%]	Not significant
Reducing pain	22[11.7%]	9[40.9%]	13[59.1%]	
Don't know	19[10.1%]	11[57.9%]	8[42.1%]	
Discontinuation of ART				
Yes	171[91.0%]	102[59.6%]	69[40.4%]	P<0.05[0.948]
No	17[9.0%]	10[58.8%]	7[41.2%]	Not significant
Believes ART is effective				
Yes	128(68.1%)	77[60.2%]	51[39.8%]	P<0.05[0.814]
No	60(31.9%)	35[58.3%]	25[41.7%]	Not significant
ART improves the quality of life				
Yes	130(69.1%)	76[58.5%]	54[41.5%]	P<0.05[0.644]
No	58(30.9%)	36[62.1%]	22[37.9%]	Not significant

Source: Primary data

4.5 Association of Adherence to the Treatment related factors of the Caregivers

99(52.7%) of the caregivers agreed that their children had experienced side effects whereas 89(47.3%) of the children had never experienced any side effects. Most of the children 59[66.3%] who had never experienced side effects were reported as adherent to their ART treatment. Side effects of ART though had no significant statistical association with adherence outcomes $P < 0.05$ [0.076]. Table 4:

Majority 125(66.5%) of the caregivers had their children on Directly Observed therapy because of the ART regimen complexity whereas 65(33.5%) of the caregivers did not have their children on Directly Observed therapy. Also worth noting, more than half of the children 74[59.2%] who were on the directly observed therapy were reported as adherent. However regimen complexity had no significant association with adherence outcomes $P < 0.05$ [0.844].

It was evident that majority 140(74.5%) of the caregivers admitted that their children required food to take their ART treatment and 48(25.5%) of the caregivers reported that their children did not require food to take their ART medications. Nearly three quarters 86[61.4%] of the caregivers who admitted that their children required food to take their ART treatment, the children were adherent as compared to 26(54.2%) of the children whose care givers reported that their children did not require food to take their ART. However from this study dietary restrictions had no significant association with adherence outcomes ($P < 0.05$) [0.379].

Table 5: Association of Adherence to the Treatment related factors of the Caregivers

Independent variable	Frequency	Non adherent	Adherent	Statistical test
Side effects of ART medication.				
Yes	99(52.7%)	53[53.5%]	46[46.5%]	$P < 0.05$ [0.076]
No	89(47.3%)	59[66.3%]	30[33.7%]	Not significant
Directly Observed Therapy				
Yes	125(66.5%)	74[59.2%]	51[40.8%]	$P < 0.05$ [0.844]
No	63(33.5%)	38[60.3%]	25[39.7%]	Not significant
Takes ART treatment with food				
Yes	140(74.5%)	86[61.4%]	54[38.6%]	$P < 0.05$ [0.379]
No	48[25.5%]	26[54.2%]	22[45.8%]	Not significant

4.6 Association of Adherence to the Health care system related factors of the Caregivers

The majority 89(47.3%) of the caregivers were living within a distance of less than 5 kilometers, 43[22.9%] 6 – 10 kilometers and 56[29.8%] were staying in a distance of more than 10 kilometers from Kisugu health center III. However the distance to health facility had no significant statistical relationship with adherence outcomes $P < 0.05$ [0.566].

Minority 59[31.4%] of the caregivers reported experiencing shortage of drugs at the clinic. Nearly three quarters 129[68.6%] of the caregivers reported not ever witnessing drug shortages at the clinic. Availability of medication had no significant association with adherence outcomes $P < 0.05$ [0.061].

Majority of the caregivers 124[66.0%] indicated that they had received complete and necessary information on ART treatment in relation to their children and only 64[34.0%] reported that they did not receive complete information on ART treatment. ART counseling services had a significant association with adherence outcomes ($p < 0.05$) [0.000]. Table 5:

On the caregiver health care provider relationship, the majority of the caregivers 117[62.2%] indicated that they were satisfied with health care provider staffs and only 71[37.8%] caregivers were not satisfied with health care provider staffs. Satisfaction with health-care provider staffs had no significant association with adherence outcomes $P < 0.05$ [0.410].

It was evident that nearly all of the caregivers 175[93.1%] indicated that the hospital staffs offered a friendly environment and only 13[6.9%] reported that hospital staffs did not offer a friendly environment. Hospital staffs offering a friendly environment had no significant association with adherence outcomes $P < 0.05$ [0.309].

On follow up, majority of the caregivers 128[68.1%], reported that they had been initiated on a follow up program conducted by health workers. Follow up did not reflect a significant association with adherence outcomes ($p < 0.05$) [0.814].

Regarding waiting time at the clinic, most of the caregivers 129[68.6%] indicated that they spent long waiting hours at the clinic and less than half 59[31.4%] of the caregivers indicated that they spent short waiting hours at the clinic. However waiting time did not reflect any statistical significant association with adherence outcomes $P < 0.05$ [0.316].

Table 6: Association of Adherence to the Health care system related factors of the Caregivers

Independent variable	Frequency	Non adherent	Adherent	Statistical test
distance to health facility				
Less than 5km	89[47.3%]	56[62.9%]	33[37.1%]	P<0.05[0.566]
6 - 10 km	43[22.9%]	23[53.5%]	20[46.5%]	Not significant
>10 km	56[29.8%]	33[58.9%]	23[41.1%]	
Shortage of drugs at the clinic				
Yes	59[31.4%]	41[69.5%]	18[30.5%]	P<0.05[0.061]
No	129[68.6%]	71[55.0%]	58[45.0%]	Not significant
Counseling				
Yes	124[66.0%]	85[68.5%]	39[31.5%]	P>0.05[0.000]
No	64[34.0%]	27[42.2%]	37[57.8%]	Significant
Satisfied with health care providers				
Yes	117 [62.2%]	67[57.3%]	50[42.7%]	P<0.05[0.410]
No	71[37.8%]	45[63.4%]	26[36.6%]	Not significant
hospital staffs offer friendly environment				
Yes	175[93.1%]	106[60.6%]	69[39.4%]	P<0.05[0.309]
No	13[6.9%]	6[46.2%]	7[53.8%]	Not significant
Follow up				
Yes	128[68.1%]	77[60.2%]	51[40.2%]	P<0.05[0.814]
No	60[31.9%]	35[58.3%]	25[41.7%]	Not significant
Waiting time				
Short	59[31.4%]	32[54.2%]	27[45.8%]	P<0.05[0.316]
Long	129[68.6%]	80[62.0%]	49[38.0%]	Not significant

Source: Primary data

**CHAPTER FIVE:
DISCUSSION OF RESULTS**

5.0 Introduction

This chapter presents the discussion of the results of the findings from the study. The discussion is presented in two parts as demographic characteristics of the study population and in accordance with the independent variable of the study.

5.1 Discussion

This study found an estimated prevalence of adherence to ART treatment in children attending Kisugu Health Center III AIDS clinic at 59.6%. Only 59.6% of the caregivers administered 100% of the medication one week preceding the study. This is comparable to findings in Brazil conducted by Ferreira et al, (2013) that estimated the prevalence of adherence to ARV treatment in children living in Porto Alegre at 59.5% and comparable to findings in West Africa, with 58% of the caregivers declared perfect adherence (Julie *et al.*, 2008).

5.2 Association of Adherence to Socio - demographics factors of the Caregiver and Child.

Caregivers' age was not significantly statistically associated with adherence. It was however observed that prevalence of adherence was low among caregivers below 20 and those over 51 years of age. These have low capacity or low ability to adhere, as adherence is dependent on having the necessary cognitive and technical skills to follow a medication scheme, perceived self-efficacy and problem solving capacity. These results compare with studies revealed that caregivers of young age were not significantly associated with low level of pediatric adherence to ART (Beer *et al* 2012).

This study showed no significant association between the caregiver's gender with adherence. A higher percentage of male caregivers, however, showed more adherent cases than the female. This can be explained by the fact that even when married, the burden of running the home is most often on the woman's shoulder. Women are thus overburdened with responsibility and where there is no support, can easily forget to administer treatment to the child. Where the women are single and have the additional task of fending for the family, the risk of non-adherence is high. Women thus whether single or married have difficulty coordinating adherence with work, family or care giving responsibility. These results compare with a study in West Africa where female caregivers were associated with low level of adherence (Fumaz *et al* 2008).

There was a slight difference in adherence between those married and those living single. It is assumed that if married, caregivers should be able to cope with ART administration as responsibility for drug administration is shared. Adherence prevalence should be higher among the married caregivers". This

was however not the case in this study. The slight difference would be attributed to the ability of married couples to share the work load, even with busy schedules that is helping each other meet the financial demands of providing care by either combining their income or dividing the duties, these findings combined enabled children cared for in these circumstances to adhere more to their ART. These findings are not supported by a cross sectional study in Botswana by *Makhema, et al. (2013)*.

Better caregiver's education was independently associated with better adherence. The findings suggest that caregivers overall education impacts more on the treatment adherence. These findings are supported by *moralez et al., (2009)* who also concluded that better caregivers' education was strongly independently associated with better adherence. The level of education is an important indicator of one's cognitive and technical skills therefore caregivers who have low levels education do not quickly appreciate the importance of strict adherence to treatment.

Caregiver's relationship to the child was independently associated with child adherence in this study. Children cared for by guardians had a slightly higher prevalence of adherence. One of the explanations of this observation could be that the guardians were more committed to giving the children medication because they readily and willingly accepted the responsibility of the child's care, thus the child was not a burden to them. These findings are in line with a study carried out by (*Pontali, 2015*). It is thus important that the team that treats the child be aware of the quality of the relationship between the caregiver and the child, and should involve other family members in the management of the child's disease where necessary.

Children under 5 years of age recorded a slightly higher adherence prevalence compared to those over 5 years of age. Children under 5 years of age pose a challenge to adherence as they are known to spit the drug especially if unpalatable, or simply refuse to take medication; sleep patterns can also interfere with administration of medication therefore given much attention. There was, however, no statistically significant association between adherence and "age of the child". This concurs with a study conducted in South Africa, where the same characteristics were shown not to be associated with adherence/non-adherence (*Nakashima et al 2009*).

A higher prevalence of adherence was observed among the male children. Sex of the child did not show any association with adherence. These results compare with a study in china where female children were more likely to miss visits during the first 6 months of ART initiation (*Ying Liu, 2013*). The explanation

for this is not clear, but it could be explained, partly by cultural norms and taboos. In Tanzania, girls are more engaged in household activities than boys. In the course of accomplishing the given tasks, they might end up tired and hence forget to take their pills, resulting in poor adherence.

5.3 Association of Adherence to Psycho social factors of the Caregiver.

The caregiver's financial status in this study had no significant association with adherence. However, it was observed that majority of the caregivers who had difficulty adhering to medication were in the lowest income level, with those in the highest income levels displaying high adherence prevalence. *Maridadi, (2008)* concluded that better caregiver socio-economic status was strongly associated with adherence. Poverty has been shown to place families at increased risk for many stressful life events and has been shown to be strongly associated with child non-adherence (*Brigido, et al., 2008*)

Stigma and Discrimination in this study had no significant association with adherence. However this study findings revealed that majority of the caregivers were stigmatized upon community learning of their child's status. Most of the community members have a poor attitude towards caregivers living with children infected with HIV/AIDS which therefore implied that some community members did not value the work done by the caregivers looking after HIV/AIDS infected children in their families and this sometimes stigmatizes the caregivers. This is supported by *Valdez et al., (2008)* who revealed that caregivers have significant social stigma described in different ways: shyness, fear of being laughed at with their children, fear of being embarrassed, which would partially or completely disrupt the child's drug adherence levels because they are considered to have the disease and would spread it to others.

Knowledge of care-givers about ART, in this study was not statistically associated with adherence outcome. However the majority of the caregivers knew the role of ART as they noted that ART reduced the progression of AIDS, which is true hence shows that most caregivers were knowledgeable about ART since more than half of the caregivers in their opinion indicated to never discontinue the children from ART once the symptoms of HIV/AIDS disease improved. These findings concur with a study conducted South Africa by *Murray et al (2009)*.

Disclosure of child's HIV status in this study was not significantly associated with adherence. Other studies have also showed no effect of disclosure on adherence to ART (*Moodley et al., 2010*). These study findings revealed that majority of the caregivers were not willing to disclose that HIV sero –

positive status of the child. This would be explained by the fact that HIV diagnosis disclosure entails communication about a potentially life threatening, stigmatized and transmissible illness and many caregivers fear that such communication may create distress for the child. These findings are not in line with a cross-sectional study conducted by (*Wiener et al., 2009*).

Social support was independently associated with child adherence in this study. Other studies also supported that social support is associated with child adherence (*Williams et al, 2014*). Regardless of the type of support received, support empowers the caregivers to take full responsibility of their children and better plan how to help their children adhere to ART. This concurs with a study conducted by *Weidle PJ et al., (2011)*, where the same characteristics were shown to be associated with adherence.

This study showed no significant association between the caregiver's attitude and beliefs towards ART. However from this study a higher percentage of the caregivers who believed in the efficacy of ART treatment had better adherence outcomes. This could be partly explained by the fact that a belief in the efficacy of ART cultivates faith in the treatment regime therefore caregivers who deny their child's infection are less likely to be invested in adherence. The findings confirm those of previous studies (*Mills et al. 2011*) concerning these factors.

5.4 Association of Adherence to Treatment related factors.

Side effects of ARV drugs had no significant association with adherence, however the study found out that, children who experienced side effects were more likely not to adhere to ART than those who did not experience side effects. These findings concur with *Rubel et al, (2011)* and *Rosen et al, (2010)* who revealed that side effects appeared to be a relatively less common reason for disengagement from care. This could be explained by regimen associated toxicity and drug hypersensitivity which is far more common in children with HIV.

Aspects related to treatment regimen complexity were of no significance in as far as adherence is concerned in this study. These findings are similar to findings from a study in Brazil showed that the "time of use" and "number of drugs composing the therapeutic regimen" had no relationship with non-adherence (*Naiva et al., 2009*). However there were a slightly higher percentage of children who were affected by the complexity of the regimen and were non adherent. This was due to the physical aspects of particular medication, taste , size, formulation, pill burden ,frequency of dosing and need for daily

administration.

Dietary restrictions in this study had no association with adherence. However, it was observed that majority of the children who did not have difficulty adhering to medication required food to take their ART drugs; this is because some paediatric ART formulations require dosing on a fasted stomach hence find their meal schedule compromised by ART drugs thus adjustments in lifestyle. These findings concur with a cross sectional study conducted by (*Grieson, et al., 2010*).

5.5 Association of Adherence to Health care system related factors.

Distance to health facility in this study had no significant association with adherence. The study findings show that caregivers to children who were coming from a distance of 10 kilometers or less were more adherent compared to those coming from more than 10 kilometers. Those who were coming from a short distance were taking their drugs as expected as opposed to those from distant places who were missing drugs because of distance, weather problems and lack of funds to transport the caregivers to the health center IV. Most caretakers who come from far move on foot which is a challenge to most caregivers who have to move with their children. *Makombe, (2010)* also found out a similar situation in Malawi, were caregivers had to travel very long distances to access drugs for their children.

The study findings revealed that availability of drugs at the health center had no influence on adherence to ART among children. This is because there were no drug stocks running out; many children on ART could maintain their ART regimen and thus an increase in adherence to ART. These results did not concur with findings from (*Grierson, 2010*).

The study found out that counseling services to the caregivers had a bearing on the adherence levels among children on ART. The caregiver's who received complete information on ART treatment their children were more adherent compared to those who did not receive complete information on ART treatment. This is because the caregiver's were confident and had accurate information about the child's HIV/ART medication, dosages and dosing frequencies hence the ability to administer the treatment successfully. This finding is in line with a study conducted in India by *Mathur, (2010)*

This study found out that good caregiver health care provider relationship had no significant relationship on the adherence levels among children on ART. Caregivers to children who were satisfied with health care providers at the health center, the children had better adherence. This was because the

children and caregivers were more willing to be advised and counseled by welcoming and friendly health workers who gave them attention, treated them like human beings and not those who avoided and stigmatized them. This good attitude encourage the caregivers to come back and seek counsel and advice in regards to their children's medical and food regimen which led to more adherence levels to ART. This finding concurs with a study conducted by *Bultman, (2008)* in Washington DC.

This study found out that follow up had no significant relationship on adherence, however the caregivers who were enrolled on a follow up program organized by the health workers there children had better adherence compared to those who had not enrolled, this is because caregivers were more actively involved in planning on how to help their children adhere to ART treatment. Through follow up, caregivers were actively involved in reminding among other measures which were suggested to improve adherence. This finding is in line with a cross sectional study by *Williams et al, (2014)*.

Waiting time in this study had no significant association with adherence outcomes. The study revealed that majority of the caregivers had experienced long waiting hours at the clinic, and their children had poor adherence levels. This is because caregivers were discouraged to be advised and counseled after waiting for long hours. Waiting for a long hour is stressful, hence some caregivers felt discouraged to visit the health centre. These findings are in line with studies conducted by *Maokisa (2012) and Martin (2010)*.

CHAPTER SIX:

CONCLUSIONS AND RECOMMENDATIONS

This chapter presents the conclusion drawn from the study findings and gives recommendations as to the way forward on how the problem of adherence to ART among children can be handled.

6.0 Conclusion

This study shows that adherence to ART among children at Kisugu Health Center III is definitely a challenge, given the low prevalence of adherence. It is concluded that the majority of caregivers in this setting are unable to attain optimal adherence.

The socio – demographic factors of the caregivers such as age, gender, children under care, occupation status and marital status did not show any meaningful association with adherence. The age of the child under care and gender, were also not of importance as far as adherence is concerned. However caregiver education level and child caregiver relationship were positively and independently associated with adherence hence a predictor of adherence.

Among the psycho-social factors studied, social support improved a child’s level of adherence to ART therefore social support was independently associated with adherence thus a predictor of adherence.

Health care system related factor such as ART counseling services were associated with adherence hence is a predictor of adherence among children.

None of the treatment related factors was significantly associated with adherence to ART among children.

6.1 Recommendations

Based on the study findings, the study recommends the following;

The importance of adherence in this setting needs to be emphasized if the benefits of ART are to be observed. Caregivers in this setting need further education on the importance and benefits of adherence. There is also need for close monitoring of adherence in this setting.

It is important for health-care givers to consider the primary caregivers’ level of education as this will be a key guide in assessing the ability to adhere to the child’s medication regimen. Irrespective of the level of education of the caregiver, the importance of intensive education about HIV, ARV medication and relevance of adherence to ART should be underscored before initiation of treatment.

There is need for public support to the families with sero positive children. There is a need for financial support for the caregivers to sero positive children so as they are able to have ready transport to visit the hospital whenever necessary and as well buy the necessary foods to supplement their diet.

The researcher recommends that hospital authorities should advocate for an increase in the number of health workers providing ART services so that children caregivers to sero positive children can get quick and better services.

In order to facilitate adherence comparisons in the different settings, there is need for standardization of procedures to assess adherence/non-adherence, with clear adherence cut off points.

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APPENDIX II:
CONSENT FORM

Dear respondent,

I Echiru Andrew, a student of International Health Sciences University pursuing a degree in nursing science, I am conducting a study on **Care giver factors associated with Adherence to antiretroviral therapy among HIV infected children at Kisugu Health Center III**

You have been selected on merit for your legibility to provide necessary information required. However, any information to be provided will be used mainly for academic purposes and will be treated with utmost confidentiality.

Your participation is entirely voluntary, you have rights to decline to participate, to withdraw any statement before analysis or discontinue your participation and this will not affect you in anyway. There are no physical benefits for participation in this study but findings will help in coming up with strategies to improve menstrual hygiene among adolescents in secondary schools.

Signature of researcher.....

Respondent

I hereby confirm that I understand the contents and nature of the document and therefore consent to be interviewed by this researcher carrying out the above mentioned study. I have been assured of total confidentiality, and that the results of this study shall not identify me anywhere in any way since my name is not needed and it shall not appear anywhere in this questionnaire. And in any case, my refusal to answer questions shall not affect me or any member of my family.

Signature of respondent

Date

APPENDIX III:

QUESTIONNAIRE

SECTION A: SOCIO-DEMOGRAPHIC FACTORS

Caregiver

1. What is the age of care-giver in years?
20 and below []
21 - 30 []
31 - 40 []
41 - 50 []
51 - 60 []
61 and above []
2. What is the sex of the care-giver?
Male []
Female []
3. What is the care-givers level of education?
No formal education []
Primary level []
Secondary level []
Tertiary Level []
4. What is the care-givers current marital status?
Single (no partner) []
Married []
Divorced []
5. How is the caregiver related to the child?
Parent: mother []
Father []
Guardian []
Foster care []

Child

6. What is the age of the child?

0 – 5 years []

6 – 12 years []

7. What is the sex of the child?

Male []

Female []

Prevalence of adherence

8. Has your child ever missed a dose of a medication in the last week preceding study?

Yes []

No []

9. If yes, what were the reasons for missing the medications?

Forgetfulness []

Being busy []

Inter current illness []

Child refused []

Did not refill []

Feeling better []

SECTION B: PSYCHOSOCIAL FACTORS

10. Employment?

Full time employment []

Part time employment []

Self employed []

Unemployed []

11. Do you get support from relatives, friends and other people?

Yes []

No []

12. If yes mention, the form of support you receive?

.....
.....

13. Are you willing to disclose the status of your child?
Yes []
No []
14. Have you ever encountered secondary stigma in the community as a result of providing care to children infected with HIV/AIDS?
Yes []
No []
15. In your opinion what is the role of the ARV drugs?
Reducing progression of HIV []
Curing HIV []
Reducing pain []
I don't know []
16. In your opinion does ART therapy need to be discontinued once the symptoms of HIV disease improve?
Yes []
No []
17. Do you believe ART improves the quality of life of the child?
Yes []
No []
18. Do you believe ART is effective in management of HIV/AIDS?
Yes []
No []

SECTION C: TREATMENT RELATED FACTORS

19. Does your child experience any form of side effects after swallowing ARV drugs?
Yes []
No []
20. Is the child on Directly Observed Therapy [DOT]?
Yes []
No []
21. Does your child take ART treatment with food?
Yes []
No []

SECTION D: HEALTH CARE SYSTEM RELATED FACTORS

22. What is the distance to health facility from where you stay?

Less than 5km []

6 - 10 km []

>10 km []

23. Has there ever been shortage of ART drugs at the clinic?

Yes []

No []

24. Were you given complete information on ART treatment?

Yes []

No []

25. Do the hospital staffs offer friendly environment while caring for your children?

Yes []

No []

26. Are you satisfied with health care provider staffs serving at the clinic?

Yes []

No []

27. Are you enrolled in any follow up program organized by health workers to monitor the progress of your child towards ART adherence?

Yes []

No []

28. What is the waiting time for medication refill at clinic?

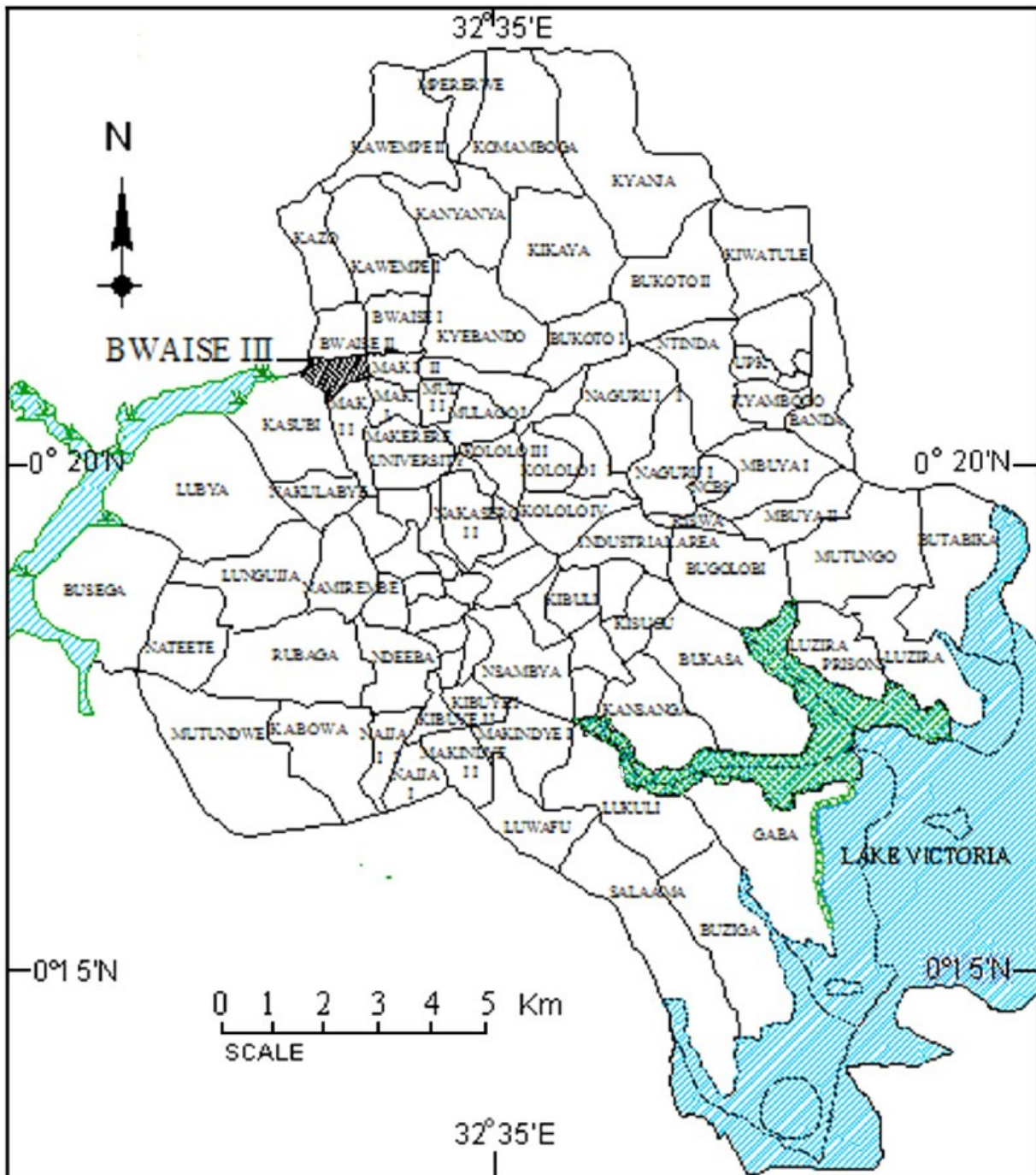
Short []

Long []

THANK YOU ONCE AGAIN FOR YOUR RESPONSES

APPENDIX III:

MAP OF KAMPALA SHOWING LOCATION OF KISUGU HEALTH CENTER III



APPENDIX IV
INTRODUCTORY LETTER



making a difference in health care

Office of the Dean, School of Nursing

Kampala, 1st November 2016

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

Dear Sir/Madam,

RE: ASSISTANCE FOR RESEARCH

Greetings from International Health Sciences University.

This is to introduce to you **Echiru Andrew**, Reg. No. **2012-BNS-FT-033** who is a student of our University. As part of the requirements for the award of a Bachelors degree in Nursing of our University, the student is required to carry out research in partial fulfillment of his award.

His topic of research is: **Caregiver factors associated with adherence and retention to anti-retroviral therapy among HIV infected children at Kisugu Health Center III**

This therefore is to kindly request you to render the student assistance as may be necessary for his research.

I, and indeed the entire University are grateful in advance for all assistance that will be accorded to our student.

Sincerely Yours,



Ms. Agwang Agnes
Dean, P.O. Box 7782, Kampala - Uganda

The International Health Sciences University
P.O. Box 7782 Kampala – Uganda
(+256) 0312 307400 email: aagwang@ihsu.ac.ug
web: www.ihsu.ac.ug

APPENDIX V
CORRESPONDENCE LETTER



**DIRECTORATE PUBLIC HEALTH
AND ENVIRONMENT**

REF: DPHE/KCCA/201/17

13th July, 2016.

Mr. Echiru Andrew
International Health Sciences University,
P. O. Box 7782,
Kampala.

**RE: PERMISSION TO CONDUCT RESEARCH AT KISUGU
HEALTH CENTRE III ON THE TOPIC " CARE GIVER
FACTORS ASSOCIATED WITH ADHERENCE TO ART
AMONG HIV INFECTED CHILDREN AT KISUGU HEALTH
CENTRE III**

Reference is made to your letter dated 28th June, 2016 requesting for permission to conduct research on the above research topic.

This is to inform you that permission has been granted to you to conduct research at Kisugu Health Centre III for two (2) weeks from 14th to 23rd July, 2016.

The above permission is granted to you on the following conditions:-

1. Participation in your research is voluntary and the informed consent process should be observed at all times.
2. Provision of a report to the office of the Director, Public Health and Environment

P O. Box 7010 Kampala- Uganda
Plot 1-3 Apollo Kagawa Road
Tel: 0414 231 446 / 0204 660 000
Web: www.kcca.go.ug Email: info@kcca.go.ug
Facebook: www.facebook.com/KCCAUG

By copy of this letter, the In-Charge Kisugu Health Centre III is requested to render you all the necessary support.


Dr. Julius Simon Otim
FOR: DEPUTY DIRECTOR MEDICAL SERVICES

c.c. Director Public Health and Environment
c.c. In-Charge, Kisugu Health Centre III