FACTORS INFLUENCING NON-ADHERENCE TO ANTIRETROVIRAL THERAPY AMONG HIV INFECTED YOUTH PATIENTS ATTENDING KANGEMI AND COPTIC HEALTH HIV/AIDS CLINICS IN NAIROBI, PROVINCE, KENYA

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DECLARATION

This proposal is my original work and has not been presented for a degree in any other university.

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DEDICATION

I dedicate this work to my loving wife Dr Natalia Gitu, whose support and encouragement never wavered all through the stress and demand of combining my work, family and academic pursuits.

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DEFINITION OF TERMS

AIDS	Acquired Immunodeficiency Syndrome caused by systematic depreciation of CD4 cells by HIV.
CD4	This refers to an antigen maker of helper/inducer T cell that recognises antigens bound in class II MHC protein.
Incidence	The incidence of a disease is defined as the number of new cases that occur during a specified period of time in a population at risk for developing the disease.
Mean adherence	Proportion of those who take their medication ≥ 95% of the time.
Non-adherence	Non-adherence to ART means not taking prescribed ARVs doses at all, the right time and without any dietly observation.
REACH	Reaching for Excellence in Adolescent Care and Health
Sub-mean adherence	Proportion of those who take their medication <95% of the Time

Undetectable Viral Load	When the virus is not detected in the blood after a laboratory test.
Variable	The variable is a mathematic statement whose value, when specified determines the value of another variable or other variables
Dependent Variable	A variable whose values are dependent on other values
Independent Variable	A variable whose values are independent of changes in the values of the other variable
Viral load	Levels of virus found in the blood per 10 millilitres (mls).
Youth	The age group from 15-25 years.

ABBREVIATIONS AND ACRONYMS

ANC	Antenatal Clinic
ART	Anti-retroviral Therapy
ARV	Anti-retroviral (Drug)
CCC	Comprehensive Care Centre
CDC	Centre for Disease Control and Prevention
DAART	Directed Active Anti-retroviral Therapy
FBO	Faith Based Organization
GOK	Government of Kenya
HAART	Highly Active Anti-retroviral Therapy
HIV	Human Immunodeficiency Virus
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome
KDHS	Kenya Demographic and Health Survey
KNASP	Kenya National HIV/AIDS Strategic Plan
KNH	Kenyatta National Hospital
M & E	Monitoring and Evaluation
MCH	Maternal and Child Health
MOH	Ministry of Health
NACC	National AIDS Control Council
NASCOP	National AIDS and STI Control Council

NCAPP	National Coordinating Agency for Population and Development
NGO	Non-Governmental Organization
NART	Nucleoside Analogue Reverse Transcriptase
NNRT	Non-Nucleoside Reverse Transcriptase
O/P NO	Outpatient Number
OIs	Opportunistic Infections
PEPFAR	President's Emergency Plan Aids Relief
PI	Protease Inhibitor
PLWHA	People Living with HIV and AIDS
SSA	Sub -Saharan Africa
SPSS	Statistical Package of Social Sciences
STI	Sexual Transmitted Infections

ABSTRACT

HIV remains a global health problem of unprecedented dimensions. Unknown 27 years ago, HIV has already caused an estimated 25 million deaths worldwide and has generated profound demographic changes in the most heavily affected countries. Young people aged 15–25 account for an estimated 45% of new HIV infections worldwide. Antiretroviral therapy (ART) requires a high-level (> 95%) adherence. Kenya is scaling up ART access programmes to the HIV infected youth, however, significant proportions of HIV-infected youth patients have high levels of non-adherence and this can lead to devastating public health problems. Published data on non-adherence to ART among the youth in Nairobi is limited. The objective of this study was to determine important factors influencing non-adherence to antiretroviral therapy among HIV/AIDS male and female youth attending Coptic (Ngong road) and Kangemi Health Centres, Nairobi, Kenya. A cross-sectional study involving 300 youth HIV/AIDS patients attending Coptic (Ngong road) and Kangemi Health Centres between August and December 2010 was conducted. These youth patients were on ARV drugs. Data were collected from the respondents using interviewer–administered questionnaires to patients and self-administered questionnaires to ten key informants (nurses and clinicians in charge of HIV/AIDS clinic) selected by purposive sampling. The key variables examined were demographic, other characteristics of the patients and non-adherence factors. Data were analysed using Statistical Package for Social Sciences (SPSS) version 17.0 for frequencies, cross-tabulations and Chi-Squared test and statistical significance set at $p<0.05$ Results show that the prevalence of non-adherence to ART was 30% according to visual analogue scale and 6% by four-day self-report recall. Factors that were significantly associated with non-adherence were costs of transport ($\chi 2 = 8.147$, df = 1, P = 0.004), age of respondent ($\chi 2 = 26.27$, df = 10, p=0.003),occupation ($\chi^2 = 26.427$, df=1, p=0.0001), ART regimen($\chi^2 = 20.656$, df=1, p=0.0001) stigma ($\chi^2 = 10.526$, df=1, p=0.001) and ability to follow treatment instructions ($\chi^2 = 23.732$, df=1, p=0.0001). The study showed that being young, not employed, having no money for transport, having stigma on ART, unable to follow treatment instructions and being on ART regimen influenced non-adherence to ART. In conclusion, HIV/AIDS infected youths attending Coptic and Kangemi Health Centres have high non-adherence rates to ART according to visual analogue scale and four-day self-report recall. To improve ART adherence among the youth, the study recommends to the government to consider social-economic subsidies such as transport vouchers to patients who genuinely cannot afford the cost of transport to collect their medications, develop strategies to reduce unemployment among the youth and intensify promotion against stigma surrounding AIDS patients.

CHAPTER ONE: INTRODUCTION

1.1 Background of the Study

HIV remains a global health problem of unprecedented dimensions. Unknown 27 years ago, HIV has already caused an estimated 25 million deaths worldwide and has generated profound demographic changes in the most heavily affected countries. Globally, there were an estimated 33 million people living with HIV in 2007 (UNAIDS, 2008).

Young people aged 15–25 account for an estimated 45% of new HIV infections worldwide (UNAIDS 2007). Kenya is among the countries in sub-Saharan Africa with the largest HIV 1.4 million out of Kenya's population of 36 million are living with HIV or Acquired Immune Deficiency syndrome (NACC, 2008).

Results from KAIS, 2007 indicate that 7.4% of Kenyan adults aged 15-64 are infected with HIV and prevalence among youth aged 15-24 years was 3.8%. HIV prevalence in youth aged 15-24 years was 3.6% in 2003 and 3.8% in 2007, with no significant difference between these two estimates. Young women aged 15-24 years had significantly higher prevalence than young men aged 15-24 years in both 2003 and 2007. HIV prevalence in young men aged 15-19 years rose from 0.4% in 2003 to 1.0% in 2007, while in the 20-24 year age group prevalence was similar (2.4% in 2003 and 1.9% in 2007).

In recent years, the international donor community and developing countries have invested tremendously to make access to ART a reality for HIV-positive patients living in developing countries. As a result, an increasing number of HIV/AIDS youth patients have commenced ART. So far, the success of donor support to ART programs has mainly been measured in the number of HIV/AIDS patients initiating ART. However, it is important for HIV treatment programs and the international donor community to emphasise the importance of reduction of non-adherence to ART to achieve positive treatment outcomes. Failure to achieve high levels of non-adherence in ART programs will lead to an increase in the rates of treatment failure and an increase in demand for second-line treatment, which is currently ten times more expensive than first-line treatment (Hardon *et al.*, 2006). While expanding access to HIV/AIDS treatment to resource-limited settings is recognised as a global health priority, there is concern that widespread antiretroviral use could lead to widespread drug resistance. Limiting drug resistance is especially important in resource-limited settings where there are limited options for second-line regimens. Our understanding of adherence to HIV antiretroviral therapy comes from studies in resource-rich settings. Therefore, there is a very critical need to evaluate factors that determine non-adherence to antiretroviral therapy in local resource-poor settings (Byakika *et al.*, 2008).

The aim of antiretroviral treatment is to keep the amount of HIV in the body at a low level. This stops any weakening of the immune system, and allows it to recover from any damage that HIV might have caused already. These drugs are often referred to as: Antiretroviral,

ARVs or anti-HIV or anti-AIDS drugs. There are five groups of antiretroviral drugs. Each of these groups attacks HIV in a different way.

- Nucleoside/Nucleotide Reverse Transcriptase Inhibitors or NRTIs (NRTIs interfere with the action of a HIV protein called reverse transcriptase, which the virus needs to make new copies of itself) i.e. abacavir, lamuvudine, stavudine and zidovudine.
- Non-Nucleoside Reverse Transcriptase Inhibitors or NNRTIs (NNRTIs also stop HIV from replicating within cells by inhibiting the reverse transcriptase protein) i.e. delavirdine, efavirenz and nevirapine.
- Protease Inhibitors or PLs (PIs inhibit protease, which is another protein involved in the HIV replication process) i.e. indinavir, lopinavir and ritonavir.
- Fusion or Entry Inhibitors (Fusion or entry inhibitors prevent HIV from binding to or entering human immune cells) i.e. enfuvirtide.
- Integrase Inhibitors (Integrase inhibitors interfere with the Integrase enzyme, which HIV needs to insert its genetic material into human cells).

NRTIs, PIs and NNRTIs are available in most countries and are commonly used as first line treatment of ART. However Fusion/entry inhibitors and Integrase inhibitors are usually only available in resource-rich countries. They have come into existence only recently and are very expensive. They are the backbone of second-line ARVs for ART (Steigbiel *et al.,* 2008).

Treatment with ARVs is usually started on first –line treatment of ART, which comprises of drugs in NRTs, NNRTs and PLs classes. However, if after a while HIV becomes resistant to this combination, or if side effects are particularly bad, then a change to second line therapy is usually recommended. Second line therapy will ideally include a minimum of three new drugs not used by the patient before, with at least one from the new class of ARVs, in order to increase the likelihood of treatment success.

Studies have shown that consumption of more than 95% of prescribed doses was required to achieve an 80% probability of Viral Load (VL) less than 400 copies per millilitre at 24 weeks; with 90-95% adherence the probability of VL less than 400 copies per millilitre dropped to 50% (Bartlett & Gallant, 2007). Sustained viral suppression is usually associated with a rise in CD4 cell count to normal levels (immunologic improvement) after at least one year of therapy (AIDS Relief Training Slides, 2008).

Globally, there is indication that infection among young people is steadily increasing. In developing and transitional countries, 6.8 million people are in immediate need of anti-retroviral therapy now. Of these, only about 1.65 million people have access to treatment. In Kenya, over 1.4 million people are living with HIV, but the good news is that Anti-retroviral therapy (ART) has received a lot of national and international attention and support in recent years. The government of Kenya is committed to deliver ART to its citizens and according to Universal access report of 2008 and 2009, it had by 2009 given treatment to 337,050

HIV/AIDS patients in need of ART. There are currently 41,134 Nairobians aged 15 years old and above on ARVS. Strict compliance to ARV treatment is a must for long-term suppression of viral load and successful prevention and treatment of HIV and AIDS (NASCOP, 2008). The first large-scale disease progression study in the U.S. of HIV-positive adolescents infected through sexual behaviour or injection drug use, called REACH (Reaching for Excellence in Adolescent Care and Health), found that only 41% of adolescents (ages 12–19 years) on ART reported >95% adherence and that factors associated with non-adherence included depression, pill burden, advanced HIV status, alcohol use, and dropping out of school (Murphy *et al.*, 2005). In Kenya, many studies have been done on factors influencing adherence to ART among the adults and children, but surprising enough, none has been done on factors influencing non-adherence to ART among the youth in Nairobi.

1.2 Problem Statement

The Kenya AIDS Indicator Survey (2007) estimated that the average HIV prevalence among the general population aged 15-49 at 7.4 % while the Kenya Demographic and Health Survey (KDHS, 2008-09) estimated prevalence for the same population at 6.3%. The difference between the HIV prevalence estimates of the two surveys is not statistically significant given the overlap of confidence intervals. Sex differential is more pronounced among young women 15-24 age group who tend to have HIV prevalence four times higher than young men at 5.6% against 1.4% respectively (KAIS, 2007) and 4.5% and 1.1%

respectively (KDHS 2008-09). HIV/AIDS prevalence rate in Nairobi was 7.0% compared with national prevalence rate of 6.3% (KDHS, 2008-2009).

The estimated number of people living with HIV is 1.3 million to 1.6 million. New infections are estimated at 100,000 in 2009 for Kenyans aged 15 years and above (National HIV Indicators for Kenya: NACC and NASCOP, 2010). The Kenya government is offering ART for free and making sure that ARVs are available in its health clinics and also in non-governmental health facilities but in spite of this, most young patients on ART still do not comply with the strict treatment regimen. In order to have maximum suppression of the multiplication of the HIV virus and subsequent elevate the CD4 cell count, a mean level of adherence of 95% and above is required. Currently there is very little scientific data on non-adherence to treatment among the youth in Nairobi. By understanding the factors that influence the non-adherence, would contribute to the implementation of strategies that would improve the adherence rate of youth patients.

1.3 Justification of the study

While non-adherence is widely acknowledged as the most important determinant of successful ARV treatment, there is still no proven method in achieving low non-adherence rates. A major concern with scaling up of antiretroviral therapy (ART) in resource-limited settings is the emergence of drug resistant viral strains due to non-adherence and the transmission of these resistant viral strains in the population. Near perfect adherence (greater

than 95%) is required to achieve maximal viral suppression – anything less than this leads rapidly to the development of viral resistance and hence to much earlier treatment failure (WHO, 2008). With low non-adherence rates, studies have demonstrated that ART can suppress the viral load to undetectable levels, boost the immune system by increasing the number of CD-4 cells, and improve the quality of life of PLWHAS (Lewis *et al.*, 2006; Rao *et al.*, 2007).

To emphasize the significance of non-adherence, Lewis *et al* (2006) observed that a non-adherent patient is 3.8 times more likely to die than an adherent one who follows the same treatment. While the Government and other players are determined to increase accessibility to ARVs, specific initiatives towards adherence to ARVs need to be in place to ensure rational ARV use at all levels including the community level. Both Coptic and Kangemi Health Centres were not measuring levels of non-adherence among the youth. In Nairobi, Kibera a study on ART adherence showed that non-adherence was 48% among the adults (Ellis *et al.*, 2006).

1.4 Research Questions

i. What is the proportion of HIV/AIDS youth patients that do not adhere to ART instructions?

ii. Which demographic factors influence non-adherence to ART among HIV/AIDS infected youth?

iii. Which economic factors influence non-adherence to ART among HIV/AIDS infected youth?

iv. Which social-cultural factors influence non-adherence to ART among HIV/AIDS infected youth?

v. To examine how health care facilities and Health Care providers factors influence non-adherence to ART among HIV/AIDS infected youth?

1.5 Hypothesis

There are no economic, social-cultural, demographic and clinical setting factors associated with non-adherence to ART among HIV and AIDS infected youth patients.

1.6 Objectives

1.6.1 General Objectives

To investigate factors influencing non-adherence to ART among the youth infected by HIV/AIDS in Kangemi and Coptic Health Clinics in Nairobi Province, Kenya.

1.6.2 Specific objective:

i. To determine the proportion of HIV/AIDS youth patients that do not adhere to ARVs treatment instructions.

ii. To determine demographic factors that influence non-adherence to ART among HIV/AIDS infected youth.

iii. To determine economic factors that influence non-adherence to ART among HIV/AIDS youth patients.

iv. To determine socio-cultural factors that influence non-adherence to ART among HIV/AIDS youth patients.

v. To determine the effect of service of Health Care providers to non-adherence to treatment among HIV and AIDS youth patients.

1.7 Significance and Anticipated Output of the Study

Taking ARV medicines is not an easy task since it is a life treatment. It is hoped that the findings generated from this study will make several contributions to both knowledge and understandings of non-adherence to ART. The qualitative and quantitative data collected in this study will be made available to health planners such as Ministry of Health and is hoped that this will lead to better designed, better directed and more culturally sensitive intervention programs to deal with challenges associated with non-adherence. In addition, findings will assist the Ministry of Health in efforts to develop a scheme for rational use of ARVs, and also serve as a resource for future research teams developing new protocols.

1.8 Delimitation and Limitations of the Study

Since non-adherence in this study is based on oral reports and not electronic pillboxes known as Medical Events Monitoring (MEMS), there is no other objective way of verifying their level of non-adherence. Some of the respondents may give false or half-true responses in order to give a good impression of their low non-adherence level because they may be under false impression that there are rewards for low non-adherence or punitive measures like refusing to provide them with ARVs in future if they do not adhere to their medications. This also has the potential of skewing the data obtained.

CHAPTER TWO: LITERATURE REVIEW

2.1 Goals of Antiretroviral Therapy

The goals of antiretroviral therapy can be summarized as the following: improvement of the patient's quality of life, reduction of HIV related morbidity and mortality, restoration and or preservation of immunologic function and maximal and durable suppression of the viral replication (KDHS, 2008-09). It is obvious that not all patients are able to have zero non-adhere to ART. HIV is actually said to be very unforgiving in the sense, that every dose missed is noted by the virus and its genetic sequence of amino acids which promptly takes steps to evade or reduce the effect of the Anti-retroviral medications (ARVs). The reduced efficacy of ARVs will lead to virological treatment failure. It has been demonstrated that there needs to be more than 95% adherence to achieve 80% viral suppression (Bartlett & Gallant, 2007). In Africa, as we carry out expanded access to ARVs, there is concern that widespread antiretroviral use could lead to wide spread drug resistance (Volberding *et al.*, 2008).

2.2 Overview of Non-adherence to ARV

According to World Health Organization (WHO), the number of adolescents, youth on ART continues to increase, reflecting successful treatment of perinatally-infected children, infections during adolescent period, and infections during the youthful period (WHO, 2007). The scourge of HIV/AIDS in sub-Saharan Africa has led to widespread interventions with potent Anti-retroviral medications (ARVs) in a bid to counter the ravaging effects of the

rampaging virus on the human host's immune system. United States Food and Drug Administration (FDA) licensed the use of Zidovudine to treat HIV disease on March 19th, 1987and by 1992, ARVs were available for AIDS patients in developed countries, but it is only much later, by 2003, that many countries in the developing world gained access to them. Despite these successes in developing potent, life-saving ARVs, the problem of HIV infected youth patients not adhering to these ARVs still pose a huge challenge to all caregivers across the whole spectrum of HIVAIDS. Therefore, it becomes very crucial for all stakeholders involved in the care, support and treatment of HIV positive youth patients to develop very potent, user-friendly interventions. These measures will then enhance reduction of non-adherence to ART. Adherence is defined as taking doses of drugs and sticking to the treatment plan. It means taking the correct dose of drugs at the correct time and in the correct way (such as with the right type of food or fluid). Higher levels of non-adherence are associated with non-improvement of virological and clinical outcomes. Adherence rates exceeding 95% are desirable in order to maximize the benefits of ART (WHO, 2008). Non-adherence is associated with detectable viral loads, declining CD4 counts, disease progression, episodes of opportunistic infections, drug resistance, poorer health outcomes and death (Bangsberg *et al.*, 2006; Carpenter, Cooper, & Fischl, 2000; Conway, 2007; Pearson *et al.*, 2007). A study done in South Africa in 2010 on ART adherence between adolescents and adults showed that adolescents compared with adults, are less adherent to ART. They also have lower rates of virological suppression at all-time points after ART initiation, and experience more rapid viral rebound (Nachega *et al.*, 2010).

In Africa, as we carry out expanded access to ARVs, there is the concern that widespread antiretroviral use could lead to wide spread drug resistance (Volberding *et al.*, 2008).

2.3 Measurement of non-adherence to ART

Kenya health-care systems are facing exploding demand for HIV care and reliable methods for assessing non-adherence. Therefore, there is a need for effective public-health measures to improve on ART management. Non-Adherence to antiretroviral therapy (ART) is crucial in terms of viral suppression: decrease the risk of disease progression and drug resistance. However, it is difficult to measure non- adherence accurately, which is reflected in the number of conflicting reports available on the response to ART in people living with HIV/AIDS (PLHIV). Many reports on non-adherence have over-emphasised selective publication of positive results, or have been biased towards highly motivated patients with early access to limited therapy (Mills *et al.*, 2006). There are very few published reports on non-adherence on the youth. Given these methodological difficulties, it is not surprising that a surprising number of factors have been reported to influence non-adherence: age; gender; monthly income; level of education; travel time from home to clinic; baseline CD4 cell count; CDC HIV clinical stage before starting ART, type of ART regimen, presence of early ART side-effects and disclosure of HIV status to at least one relative. Studies on non-adherence to ART have tended to use pill counting, electronic drug monitoring, pharmacy refill records, biochemical markers and various self-reporting techniques such as visual analogue and self-report recall methods as a measure of non-adherence to ART (Gill,

Hamer, Simon, Thea, & Sabin, 2005). The following section explains the strength and weakness of methods used to measure non-adherence of ART.

2.3.1 Self Reporting

Self-reporting is widely used in assessing non-adherence among PLWHA. The clients are normally asked to recall and report how they have been not adhering on taking of their medication .The self-report recall period could be four days, one week or one month. This is a simple and quick tool used in measuring non-adherence especially in poor resource settings. But this method is faced by mounting concerns about its accuracy in measuring non-adherence. Some studies have shown that a patient may report to be perfectly taking his or her medicine but in actual fact, they may not be taking them (Garcia *et al.*, 2003; Population Council *et al.*, 2004).Self reporting recall measure of non- adherence has been used extensively in Kenya. The self-report recall was also used by Talam NC *et al.*, 2008 to measure ART adherence at Moi Teaching and Referral Hospital, Eldoret, Kenya, while Nyambura, 2009, on the study of factors that influence ART adherence among HIV and AIDS patients in Central Kenya, used self-reporting recall to measure adherence to ART.

2.3.2 Pill Count

Pill count is another method commonly used by health care providers in measuring non-adherence to ART. In this method of measuring non-adherence to ART, clients/patients are requested to bring to the clinic on their scheduled appointment, their medication which is then counted by the health care provider (Poppa *et al.*, 2004). The advantage of this method

is that it is cheap, simple and objective in assessing non- adherence. However, this method is faced with many issues: first, it relies on the cooperation of the client/patient to bring all the remaining medications to the clinic for counting. Secondly, the act of counting the client's medication may destroy the confidence between the provider and client as the client may feel that he or she is not trusted. However studies have shown that some patients/clients do dump or share their pills, prior to their scheduled clinic visits (Population Council *et al.*, 2004).

2.3.3 Medication Event Monitoring System (MEMS)

This is a method that uses an electronic device fitted on the lid of the medicine bottle. The electronic device records all the times the lid is opened, closed and the date. This opening and closing is assumed to coincide with taking of the medications (Poppa *et al.*, 2004; Population Council *et al*, 2004). This information is then downloaded from a computer and a written report is acquired. MEMS has the obvious advantage of objectivity, but it is faced by many issues: first, this method can lose its value, if the patient loses the lid or leaves it open for a long duration of time, secondly it is an expensive method to be used in poor resource settings and, thirdly, it may record wrongly when a patient draws a multiple dose of medicine at once which should have been taken later at different times (Garcia *et al.*, 2003).

2.3.4 Pharmacy Refill Tracking

This method utilises pharmacy refill dates to gauge non-adherence. In this method, it is assumed that patients who collect their refill of their medications regularly are adhering to

treatment (Population Council *et al.*, 2004). For this method to be effective and reliable, a proper working record keeping in the pharmacy must be in place. This method has the advantage of being simple and objective. However this method has its own short comings: one, there is an assumption that the patient would be taking his or her medication which might be contrally to what he or she might be doing, and secondly, for this method to be effective, good pharmacy record keeping is essential which is hardly the case in many poor resource settings.

2.3.5 Biological Makers

This method assesses non-adherence to ART by monitoring levels of viral load in the blood system. Since the goal of ART is to lower levels of viral load, high levels of viral load are associated with non-adherence to ART. This is a very accurate measure of non-adherence to ART but unfortunately, it is also besieged by lack of consistency. There is growing evidence that viral loads could still remain high even when the patient is adhering perfectly. This could be due to many reasons, among them being treatment failure, ARVs drug resistance and poor drug absorption (Wagner, 2001; Population council *et al.*, 2004). But the major hindrance to biological markers measure is the high cost of running laboratories, especially in resource poor settings.

2.4 Benefits of adherence to ART

A study carried out in Tanzania revealed findings which suggest that both the HIV infected person and community at large gains from good adherence to ART. HIV positive persons

are able to care for immediate members of family and dependants. The society gains by having a useful member who can participate in their daily activities (Ezekiel *et al.*, 2008).

2.5 Demographic factors that influence non-adherence to ART among HIV/AIDS infected youth

Programmatic evaluations of HIV/AIDS in resource-limited settings have historically focused on adult and child populations (Braitstein *et al.*, 2006). There is however, growing appreciation that other age groups pose a particular challenge to the provision of antiretroviral therapy. For instance, the number of adolescents on ART continues to increase. This is largely a reflection of successful treatment of perinatally-infected children, infections during early adolescence, and the expansion of access to ART worldwide (WHO, 2007).

Demographic factors such as age, higher educational levels and gender have not been found to be accurate predictors of non-adherence for other diseases (Friedland and Williams, 1999). The impact of these factors on non-adherence to ART remains uncertain. This led them to conclude that the use of such characteristics for purposes of non-adherence prediction may be influenced more by clinician bias than by patients' actual characteristics. However, Maskew *et al* (2007) found that lower levels of education were associated with higher levels of non-adherence. Gender and sex issues among the youth as barriers to ART non-adherence have not been conclusively explored. Only a few studies have drawn

conclusions on factors that facilitate women's and men's non-adherence. Watt *et al* (2009) found that opportunity to return to work, support their families, and care for their children motivated men to have low levels of non- adherence to ART. The same study also revealed that women have set schedules and since they are often bound to responsibilities of the home, it makes it easier to incorporate pill-taking. This leads them to have low levels of non-adherence to ART. Overall, the studies show some evidence, albeit small and largely qualitative, that gender issues do have an effect on non-adhere to HIV treatment and thus warrant further research on demographic factors hindering non-adherence to ART among the youth.

2.6 Economic factors that influence non-adherence to ART among HIV/AIDS youth patients

2.6.1 Poverty

Poverty is likely to affect non-adherence to ART, as financial resources may need to be directed elsewhere, where the patient/client may feel are better needed than in his/her health needs. Thus funds for travel to a medical clinic that provides ART may not be available. The combined stresses associated with poverty, such as inadequate housing, community violence and unemployment may obviate an acknowledgement of the importance of regular clinic visits.

2.6.2 Problems with access to transport

Low income countries like Kenya are characterised by poor physical infrastructure, notably inadequate transport in road, rail and water transport systems. Most patients who attend

public health clinics do not have private transport but chiefly rely on public means, which in many cases are expensive and unavailable. This factor has been shown to increase non-adherence to ART. The limited incomes characteristic of patients in low income countries may in some cases preclude even using public transport. Thus, if clinics are located far from residential townships, patients often have to walk, which may require considerable effort, particularly if they feel unwell, and this will lead to non-adherence to ART (Kagee *et al.*, 2007).

2.6.3 Unemployment challenges facing the youth

There is high unemployment among the youth in many low income countries especially in Africa. Many patients lacking regular employment make themselves available as day labourers to employers willing to pay them a wage. Often, the need for a day's wages eclipses the potential benefit of a clinic visit (Kagee *et al.*, 2007). The disincentive to seek clinic contact is exacerbated if patients are asymptomatic and have to wait for many hours to interact with a health provider in order to receive a supply of medication. Moreover, frequent absences from work create conditions under which employers may terminate employment if they do not know the reason for such absences. The threat of losing employment for this reason, therefore, often impedes clinic attendance. Most studies conducted in poor settings overlook how direct and indirect economic burdens borne by patients affect their ability to access a steady supply of antiretroviral and take them on time. Expenses of treatment like clinic visits, testing, food supplements and traveling are important barriers to treatment adherence, even when the treatment is free as it is in Uganda

(Barnett & Whiteside, 2006). This study explores economic factors influencing non-adherence to ART, particularly to understand decision-making processes of youth who do not adhere to ART and to identify conditions and circumstances that would make them have low non-adherence to ART.

2.7 Socio-cultural factors that influence non-adherence to ART among HIV/ AIDS youth patients

2.7.1 Social support

The expression of concern and encouragement from others to engage in health promoting behaviours, including medication adherence, may combine with social desirability needs on the part of the patient to yield higher rates of medical co-operation. There is strong evidence that positive social support, including being married, is associated with lower levels of non-adherence to ART (e.g. Holstad, Pace, De, & Ura, 2006; Parruti *et al.*, 2006).

ART requires life-long dedication to a healthy lifestyle, medical care and complex drug schedule, a responsibility that no one should have to endure alone. Once a patient discloses his or her HIV status to at least one person, not only does the patient relieve the burden of hiding their condition, the patient possibly gains a supporter to help manage their disease. A social supporter assists in two ways, reminding the patient to take medication and encouraging him or her psychologically. As one medical professional put it, "treatment supporters" are not a doctor or a nurse, they support, they make sure they take their pills, when (the patient) is confused; they count the pills for them (Nachega *et al.*, 2006b). A

social supporter shares some of the responsibility associated with ART, thereby relieving some of the patient's burden. Simply learning about the disease and treatment and reminding the patient to take the pills and social support has a tremendous impact on a patient's ability to lower non-adherence to ART.

2.7.2 Stigma

Persons living with HIV are often subjected to stigma and discrimination. If patients are seen by members of their social constellation, such as neighbours, family members or friends, taking ART or attending a HIV clinic, it may signal that they are HIV-positive. Often HIV-positive individuals choose to attend clinics far from their local communities to avoid being seen and identified as HIV-infected by others, thereby compounding the problems of transportation and lost time from work. One study in rural Kisesa Tanzania, which observed the uptake of the national antiretroviral treatment programme in Tanzania, found that 'fear of stigma' was a concern for all those interviewed. In particular, the participants did not want their status disclosed or expressed reluctance to identify a 'treatment buddy' as required by the programme. According to the study, "pervasive stigma remains the most formidable barrier" to taking up free antiretroviral treatment in rural areas (Mshana *et al.*, 2006). It is apparent in Kenya that the victory in countering HIV and decreasing non-adherence to ART among the youth can only be attained if the stigma linked with HIV/AIDS can be diluted. Unfortunately, social and legal challenges to human rights are undermining efforts to accomplish universal access to HIV/AIDS prevention, treatment, care, and support. One youth voiced the opinion that "the law was part of the problem"; such

a perspective could result in a reduction of individuals pursuing treatment for their infection. Kenya lacks many laws to protect people living with HIV from discrimination. Moreover, the ones that do exist are often ignored by the local police force (Wools- Kalaustian *et al.*, 2006). The studies on social-cultural factors that influence youth on non-adherence to ART shows that there remains gaps on mechanisms on how to reduce stigma to ART and there are issues on social support to youths on ARVs.The laws in place agnast discrimination are not affected.

2.8 Influence of quality of service of health care providers in relation to non-adherence to ART among HIV and AIDS youth patients

The health worker is often seen as a person in authority, in possession of specific expertise, and in whom the patient invests hope and faith for assistance in the recovery process. On the other hand, it has been shown that well-intentioned efforts by medical providers to emphasise the importance of non-adherence may actually undermine non-adherence. In a study done in South Africa, participants reported that when providers insisted on perfect non-adherence, they chose to conceal non-adherence information, as apprehension about failing to non-adhere perfectly led some of them to stop taking ART at all (Tugenberg, Ware, & Wyatt, 2006).

2.8.1 Role of Counselling

Counselling is a major source of information for a HIV/AIDS infected person and as such, it is crucial to non-adherence (Hardon *et al.*, 2006). Good ART counselling, according to the

literature, offers psychosocial support for PLWHA and encouragement in ART (WHO, 2006). HIV, AIDS and the prevention of new HIV-infections should be explained in counselling sessions by counsellors. The working mechanisms of ARVs and the significance of non-adherence should be made clear. Side-effects should be explained, as well as how to act when they occur. Furthermore, ART-counselling should address dangers of combination of ARVs with alcohol, drugs and traditional herbals. All this should happen in a context of mutual trust, privacy and respect (Hardon *et al.*, 2006).

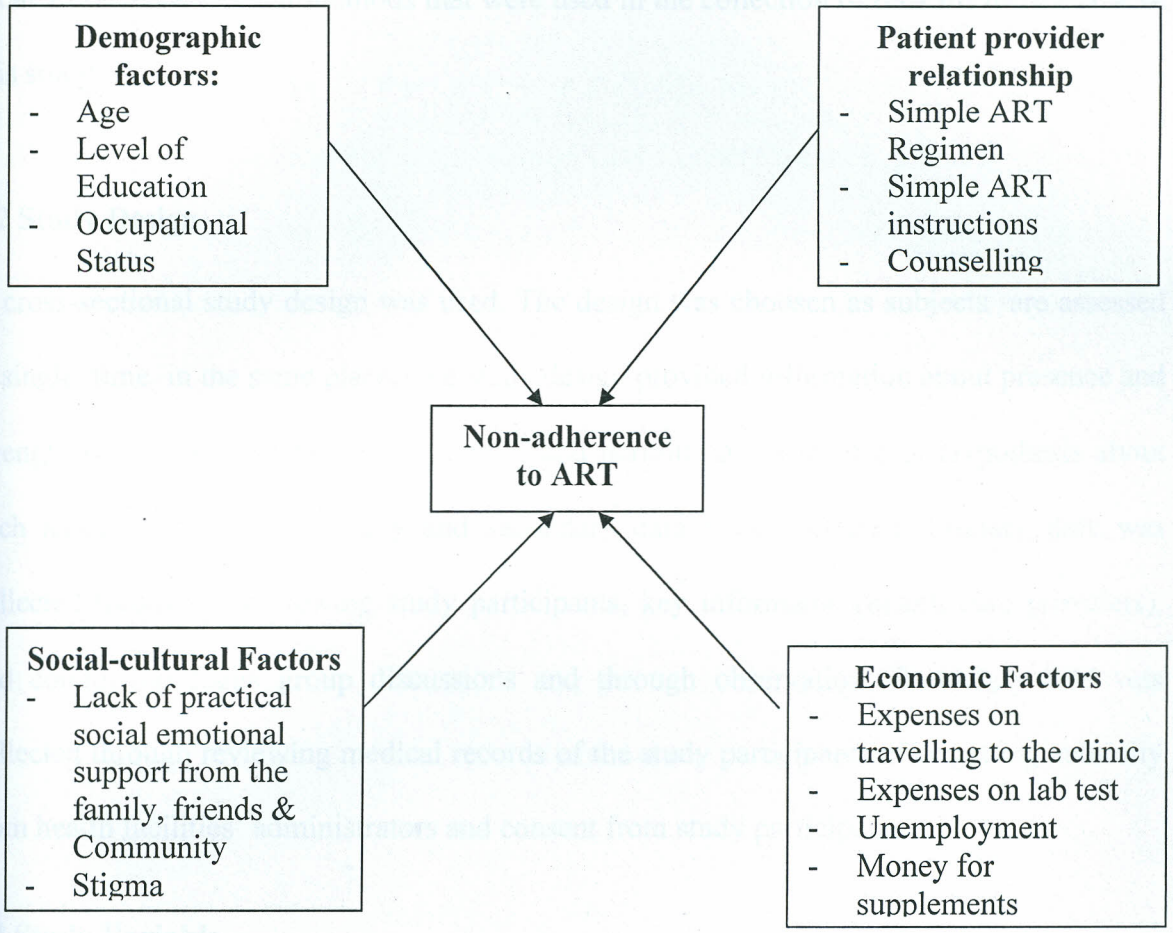
2.8.2 Choice of Regimen

The ARV regimen the patient is taking has an important role to play as several authorities have concluded that the initial regimen is the most important regimen because it is associated with the greatest probability of achieving prolonged viral suppression (Bartlett & Gallant, 2007). Hence, it is a paramount decision that the clinician chooses the most appropriate combination of ARVs combination to have a chance of high success of adherence to ART. The literature analysis reveals that gaps remain on how a medical health provider can improve on communications to HIV/AIDs patients on ART non-adherence. There is need for health providers to have deep knowledge of ARVs to give good quality service to their patients.

2.9 Conceptual Framework

Problem Analysis Diagram of possible factors contributing to non-adherence to ART.

Adopted from Chesney *et al* (2000), Kagatlwane *et al* (2005)



CHAPTER THREE: METHODOLOGY

3.1 Introduction

This chapter highlights methodological details that were used in this study. These will include the materials and methods that were used in the collection of data for the purpose of this study.

3.2 Study Design

A cross-sectional study design was used. The design was choosen as subjects are assessed at single time in the same place. The study design provided information about presence and strength of associations between variables and permitting the testing of Hypothesis about such associations. Both primary and secondary data were collected. Primary data was collected through interviewing study participants, key informants (health care providers), and conducting focus group discussions and through observation. Secondary data was collected through reviewing medical records of the study participants after getting authority from health facilities' administrators and consent from study participants.

3.3 Study Variable

3.3.1 Independent variable

Independent variables that were used in this study include: sex, age, marital status, level of education, occupation, transport cost, and treatment regimen.

3.3.2 Dependent variable

Dependent variable was non-adherence to ARVs. The key variables were examined in relationship to taking of ARVs doses.

3.4 Study Area

Nairobi province is one of the eight provinces in Kenya, the smallest in area and is entirely urban. It has only one local authority, Nairobi City Council. Nairobi is a large commercial centre both for Kenya and the East and Central African region, with good infrastructure (transport, and communication) and large market. HIV/AIDS prevalence rate in Nairobi was 7.0% compared with national prevalence rate of 6.3% (KDHS, 2008-09). According to national population census 2009, Nairobi has a population of 3.1 million inhabitants. The study was conducted in Kangemi Health Centre and Coptic Health Centre (Ngong road) in Nairobi between August and December 2010. Kangemi Health Centre had 980 HIV/AIDS youth patients on ARVs out of 3200 HIV/AIDS patients on ARVs attending the clinic, while Coptic Health Centre had 985 HIV/AIDS youth patients on ARVs out of 7325 HIV/AIDS patients attending the clinic.

3.5 Target Population

The target population was all HIV and AIDS youth patients.

3.6 Study Population

The study population was HIV/AIDS youth patients on ART attending Kangemi and Coptic health clinics in Nairobi, province Kenya in 2010.

3.7 Sampling Technique

Purposive sampling was used to select the health centres that offer comprehensive care services for PLWHA. A sampling frame (patients' register) was made. It contained names of the HIV/AIDS youth patients attending the health facilities and dates when they expected to collect their next medication. The sampling frame was organized on alphabetical order. The subjects were selected by systematic random sampling of the patient's hospital records on daily basis for the patients that were expected to collect their treatment the following day. The clinic worked from Monday to Friday every week, so we selected our subjects each afternoon for the next day. Each facility had a file room clerk, whose routine work was to prepare in the afternoon all the youth patients' hospital records that were due for treatment the next day. A sampling frame of the youth patients was then made. The sampling frame was alphabetically arranged. HIV/AIDS youth Patients on ART in the Comprehensive Care Clinics meeting the criteria were selected using systematic random sampling method, until the required sample size was obtained. The sampling interval was: K=Sampling frame (N)/Sample size (n) = 980/300=3. Kangemi Health Centre had 980 youth patients on ART out 2300 patients attending the CCC. Coptic Health Centre had 985 youth patients on ART out of 7325 patients attending the CCC.

3.8. Sample Size

Sample was determined using the following formula by Kothari (2003)

$$n=\frac{z^2pq}{e^2}$$

Where z= standard normal deviation at the required confidence level (1.96 at 95% C.I.)

p= proportion of HIV/AIDS youth patients on ART who do not adhere

q=1-p

e= acceptable error margin (precision of measurement)

p=0.25

q=0.75

e=0.05

$$n = \frac{1.96^2 \times 0.25 \times 0.75}{(0.05)^2}$$

$= 288 \approx 300$

Thus 300 youths on ART were assessed.

In addition to this, total of (Ten) 10 health workers were also interviewed in both clinics.

They were of different professions and cadres: Doctor/Clinical officer, Pharmacist/

Pharmacy technologist, Nurse, Counsellor and a Nutritionist.

3.9 Inclusion Criteria

HIV/AIDS youth patients in age group 15-25 years who have started ARV treatment and are willing to participate in the study.

3.10 Exclusion Criteria

i. HIV /AIDS youth patients in age group 15-25 who have not started ARV treatment.
ii. HIV/AIDS youth patients on ARV treatment who do not consent to participate in the study.

3.11 Research Instrument

Data for the quantitative part of the study was collected using structured questionnaire with both open and closed questions. The information that was collected included age, sex,

marital status, level of education, occupation, knowledge, attitude, perception and practice on use of ARVs by health care providers and HIV patients. Data for the qualitative part of the study was collected using focus group discussion. The purpose of the focus group discussion was to identify difficulties that were being experienced by patients on ART. In addition, key informant interviews were conducted among health care providers in comprehensive care clinics. These were Clinicians, Nurses, Pharmacists and Social Workers. A checklist was used to assess how well equipped the health facilities were. (See appendix VI).

3.12 Data Collection Technique

The study used data collecting instruments namely interviews and focus group discussion.

3.12.1 Focus groups

Two focus group discussions involving youth patients on ART were tape recorded and transcribed on two respective days, namely Thursday the 7th October 2010 in Coptic Health Clinic and Monday the 11th October, 2010 in Kangemi Health Clinic. The group discussions were for two hours each. Each FGD had 10 respondents. The focus of discussion was to find out 'the factors influencing non-adherence to antiretroviral therapy among HIV/AIDS male and female youth attending Coptic and Kangemi Health Centres, Nairobi, Kenya' bearing in mind the objectives of the study. This method of collecting data proved useful as the participants brought out their views on the topic for discussion. This proved to be cost effective as it was done over a short period of two days within the patients' schedule of

visiting the clinic. The proceedings of the focus discussions only started after a total of 20 participants were identified against a generated sampling frame (patients' register) and referred by the counsellor. The venue for focus discussion was ART clinic counselling rooms. All the participants were made to introduce themselves, and the aim of the discussion was clarified. Consent forms were handed out and participants were given a choice to leave if they did not consent. Ground rules were laid down for the group so that participants do not get distracted or get off the topic. Participants were taken through the discussion guided by the researcher using the focus group discussion guide (See appendix111). Participants were encouraged to share their views and experiences. This encouraged participants to open up not only to the researcher, but to the other participants. Participants were given refreshments which consisted of a cold drink and a scone. They were also given a pen and paper to write down important points during the discussion.

3.12.2 Interviews

Participants were contacted a day before and the venue was the ART counselling rooms. The interviews were held in the two clinics on various days, between 19th September 2010 and 10th December 2010. Interviews with the medical officer, nurse and HIV counsellor were held on same days in the morning, each lasting about 45 minutes. The interviews were guided by health provider guide (See appendix IV).

Questions on the respondents on the interview schedule were designed to focus on the research objectives. Proceedings of the interviews involved welcoming each participant and

giving a brief background of the research as well as the consent. Consent forms were handed out and participants were given a choice to withdraw if they wished, without any due duress. Later participants were given the interview question guide (See appendix 11), 10cm long visual analogue scale and given time to go through and familiarise themselves with the questions, and then asked to answers the questions. The clients were given as explanation as to what is a visual analogue (See appendix VII), and how to mark to indicate their adherence rate over the past month using a 10- centimetre long 'visual analogue' line. They were explained that the beginning of the scale is associated with complete lack of adherence in the last month, while the end is associated with complete adherence. They were then asked to mark on the top of the scale according to where their non-adherence lay. Interviews were done individually and face to face and after going through the questions, participants were given time to ask questions on issues that they did not understand, and clarifications were made.

3.13 Data Quality Control

Research instruments were pre-tested to increase validity and reliability of the responses on 30th August 2010, in Kibera Comprehensive Care Centre, 20 days before the actual study was carried. Pre-testing of research instruments was carried out. Three interviews were conducted in the morning and one focus group with 10 participants in the afternoon. This gave the researcher an experience with the procedure of using an interview schedule and focus groups as well as the recording of both. The tools were tested leading to refinement in

clarity of questions and statements, setting of time required to conduct focus groups and interviews all in line according to Christensen (2007), that pre-tested data collection tools allow for adjustment changes to be made to the data collection tools until intended results are met. The data collected was not added to the data of the study.

3.14 Data Management and Analysis

Data was sorted, coded, and entered into the computer using SPSS software version17. Data was presented using charts and frequency tables. Descriptive statistics such as mean, frequencies and percentages were used to describe and summarize the data. Thick volumes of qualitative data were collected from focus group discussions and key informants. The content was analysed eliciting recurring themes related to the research topic. A process of coding and categorization of the content of the data assisted in bringing meaning to the responses. Non-adherence rates of ART for Kangemi and Coptic Health Centres were calculated using data from four-day self-recall reports, and one month self-recall (10cm long visual analogue scale). Visual analogue scale recall for one month was developed (Appendix VII). The respondents were asked to mark a line at a point along a continuum showing how much they had adhered to ART in the last month. From the result of the visual analogue, percentage of non-adherence was calculated .The adherence rate was set at >95% and non-adherence <95%. Non-adherence in the four-day self-recall reports was calculated on the basis of whether one adhered to ART or did not adhere to ART at all. All those who did not

attain 95% of adherence were said not to have adhered to ART. Analysis of contingency tables was done and Chi-square statistic was used to test for association between variables and level of significance.

3.15 Ethical considerations

Ethical clearance was obtained from Kenyatta University and Ministry of Science and Technology (Appendix VIII) and informed consent was obtained from each study subject prior to the interview after the purpose of the study was explained to respondents. Consents were given by the guardians for those that were below 18 years. Confidentiality of the information was assured and privacy of the respondent was maintained.

CHAPTER FOUR: RESULTS

4.1 Introduction

This chapter presents results of qualitative and quantitative findings. The section covers the following findings: demographic characteristics of the study population, proportion of HIV/AIDS patients who did not adhere to treatment instructions, influence of demographic factors on non-adherence to ART, influence of economic factors on non-adherence to ART, influence of socio-cultural factors on non-adherence to ART and Health Care facility and health care providers influence on non-adherence to ART. Results of qualitative data were reported with the help of themes and categories.

Table 4.1: Distribution of respondents by demographic characteristics

The table below shows the demographic characteristics of the respondents in the study.

Patient characteristics		Frequency	Percent (%)
Gender	Male	125	42
	Female	175	58
Age	Age 15—19	68	23
	Age 20—25	232	77
Marital status	Single	214	71
	Married	86	29
Education	Secondary level or higher	150	50
	Lower than secondary	150	50

Research findings according to demographic characteristics show that more than half, 58% of the respondents in the study were females while 42% were males. The age of the respondents ranged between15 and 25 years .The age group between 15-19 years constituted 23%, while age group 20-25 years constituted 77%. The majority of the respondents were single constituting 71% of the respondents, while the rest were married accounting to 29%. Half of the respondents, 50%, had either secondary level or higher level of education, while the other half, 50%, had lower than secondary education.

4.3 Proportion of HIV/ AIDS youth patients who did not adhere to ART

Table 4.2 Distribution of non-adherence rates to ART in Kangemi and Coptic Clinics

The table below shows levels of non-adherence according to the methods used to measure non-adherence to ART in Kangemi and Coptic Health Clinics.

Findings	Kangemi Health Clinic n=150	Coptic Health Clinic n=150	Average Non-adherence
Visual line			
Non-adherence	46(30.7%) {a}	44(29.3%) {b}	90(30%) {c}
Adherence	104(69.3%) {d}	106(70.7%) {e}	210(70%) {f}
Four-day			
Non-adherence	10(6.7%) {g}	9(6%){h}	19(6.3%) {i}
Adherence	140(93.3%) {J}	141(94%) {k}	281(93.7%){l}

The non-adherence according to visual analogue was calculated as the following: a+ b/2 = c

The non-adherence according to for-day recall was calculated as the following: g+ h/ 2= i

According to visual analogue scale, 30% subjects did not adhere to ART, while according to four-day self-report recall, 6% of the subjects did not adhere. Thus, according to visual analogue scale report, there was more non-adherence than in four-day self-report recall. (Table 4.2).

4.4 Influence of demographic factors influencing non-adherence to ART

Table 4.3 Demographic factors influencing non-adherence to ART

The table below illustrates demographic factors that were influencing non-adherence to ART among the youth in Kangemi and Coptic Health Centres.

Patient characteristics		**Adherence N =246**	**Non-adherence N= 54**	**Statistical values**
Gender	Male	100 (80%)	25 (20%)	$\chi^2 = 0.581$ df= 1 P= 0.446
	Female	146 (83.4%)	29 (16.6%)	
Age	Age 15—19	66 (95.7%)	3 (4.3%)	$\chi^2 = 11.00$ df = 1 P = 0.001
	Age 20—25	180 (77.9%)	51 (22.1%)	
Marital status	Single	179 (83.6%)	35 (16.4%)	χ^2=1.368 df= 1 P = 0.242
	Married	67 (77.9%)	19 (22.1%)	
Education	Secondary level or higher	128 (85.3%)	22 (14.7%)	$\chi^2 = 2.424$ df = 1 P = 0.119
	Lower than secondary	118 (78.7%)	32 (21.3%)	

Demographic factors on non-adherence to ART in the study revealed that there was no association between sex of respondent and non-adherence to ART ($\chi 2$ =0.58, df =1,

p=0.446,). Levels of education attained by the participants revealed that there was no significant association between attained level of education and non-adherence to ART (χ^2 = 2.424 df = 1 P = 0.119).

It was also shown that as age increased, the youth were more likely to adhere to ART (χ2 =11.00, df = 1, p=0.001). Marital Status revealed that there was no significant relationship between marital status of respondent and non-adherence to ARV treatment (χ^2= 1.368, df=1, p= 0.242) (Table 4.3)

4.5 Influence of economic factors on non-adherence to ART

Table 4.4 Distribution of economic characteristics of the population interviewed

The table below demonstrates economic factors influencing non-adherence to ART among the respondents.

Characteristics of the patients		Adherence N= 246	Non-adherence N= 54	Statistic values
Transport	No difficulties in affording transport	148 (87.6%)	21 (12.4%)	χ^2 = 8.147 df = 1
	Difficulties in affording transport	98 (74.8%)	33 (25.2%)	P = 0.0004
Occupation status	Formally employed	69 (66.3%)	35 (33.7%)	χ^2= 26.427 df = 1
	Not formally employed	177 (90.3%)	19 (9.7%)	P= 0.0001
Medical insurance cover	Have medical insurance cover	23 (95.8%)	1 (4.2%)	χ^2 = 3.382
	Have no medical insurance cover	223 (80.8%)	53 (19.2%)	df= 1 P = 0.066

Most of the respondents, 56% had no difficulties with affording transport costs to the clinic while 44% of the respondents had difficulties in affording transport costs to the health clinics. Sixty-five percent of the respondents were not employed but thirty-five percent were employed. The chi-square revealed a significant association between the transport cost of the respondent to the clinic and non-adherence to ART ($\chi^2 = 8.147$, df, = 1, P = 0.0004,). There was also a significant relationship between status of occupation and non-adherence to ART ($\chi^2 = 26.427$, df = 1, P= 0.0001).This findings are shown in table 4.4.

4.6 Social-cultural factors that influence non-adherence to ART

Table 4.5 Distribution of social-cultural characteristics of the population interviewed

The table below shows the relationship between social-cultural characteristic and non-adherence to ART among the respondents of the study.

Patients characteristics		Adherence	Non-adherence	Statistic values
Stigma	There is stigma on ART	91 (71.1%)	37 (28.9%)	$\chi^2 = 17.991$ df= 1 P= 0.0001
	There is no stigma on ART	155 (90.1%)	17 (9.9%)	
Avoidance of friends	Avoided friends	114 (79.2%)	30 (20.8%)	$\chi^2 = 1.506$ df = 1 P = 0.220
	Did not avoid friends	132 (84.6%)	24 (15.4%)	
Encouragement to ART	Encouraged to ART	136 (80.5%)	33 (19.5%)	$\chi^2 = 0.611$ df = 1 P = 0.434
	Not encouraged to ART	110 (84%)	21 (16%)	

Table 4.5 shows that social-cultural factors had effects on ART adherence. The participants of the study were asked if they experienced stigma or not after being on ART. Slightly more than half of the respondents (57%) experienced no stigma about their HIV status, but 43% of them experienced stigma. There was significant association between stigma and adherence to ART (χ^2 = 17.991, df = 1, P = 0.0001,). More than half of the respondents (56%) were encouraged by friends and relatives to adhere to ART while 44% felt that they were not receiving encouragement. However, according to the study findings, there was no association between encouragement to ART and adherence to ART (χ^2=0.66, df=1, P = 0.434,).

4.7 Influence of quality services on adherence

Table 4.6 Distribution of respondents by indicators of quality of health care services

The table below shows the statiscal relationship between non-adherence to ART and effects of Health care service.

Patients characteristics		Adherence	Non-adherence	Statistical values
ART regimen	Able to follow ART regimen	217 (86.5%)	34 (13.5%)	$\chi^2 = 20.656$ df = 1 P = 0.0001
	Unable to follow ART regimen	29 (59.2%)	20 (40.8%)	
Counselling while on ART	Counselled while on ART	222 (82.8%)	46 (17.2%)	$\chi^2 = 1.189$ df = 1 P = 0.275
	Not counselled while on ART	24 (75%)	8 (25%)	
Follow-up of medical instructions	Always follow medical instructions	173 (90.1%)	19 (9.9%)	$\chi^2 = 23.732$ df = 1 P = 0.0001
	Doesn't follow medical instructions always	73 (67.6%)	35 (32.4%)	

The study revealed that 64% of respondents were able to follow ART instructions all times and 36% were unable to follow ART instructions at all times. A significant relationship existed between ability to follow ARV treatment instructions and non-adherence (χ^2 = 23.732, df = 1, P = 0.0001). There was significant relationship between ability to follow ART regimen and non-adherence. The study also revealed that ability to adhere to ART was not influenced by the respondents being counselled while on ART (χ^2 = 1.189, df = 1, P = 0.275). The respondents seem to have been well counselled before being started on ART by the medical personnel and were aware of benefits of adherence to ART (Table 4.6).

4.8 Findings of In-depth interview

The purpose of this part of qualitative study was to describe the everyday life experience of PLWHA on combination ARV therapy, explore non-adherence to ART, and formulate themes of the study. In this study, three major themes were identified namely:

- Factors contributing to non-adherence among the youth on ART
- ART regimen and instructions
- Strategies for improving adherence to ART

Table 4.7 Themes and categories

DATA DISPLAY	THEMES AND CATEGORIES	
4.1	**Theme 1**	**Factors contributing to non-adherence to ART among the youth**
4.1.1	Category 1.1	The economic burden of ART on youth was instrumental to ART non-adherence
4.1.2	Category 1.2	Stigmatization and discrimination of youths on ART
4.1.3	Category 1.3	Lack of social support on youths on ART
4.2	**Theme 2**	**ART regimen and instructions**
4.2.1	Category 2.1	Knowledge of ART regimen
4.2.2	Category 2.2	Follow-up of ART instructions
4.3	**Theme 3**	**Strategies for improving adherence to ART**
4.3.1	Category 3.1	Consideration of economic subsidies such as transport vouchers to patients who genuinely cannot afford transport cost.
4.3.2	Category 3.2	Addressing stigma and discrimination against PLHA
4.3.3	Category3.3	Simple, clear medical instructions should be the terms of instructions to ART patients.

4.8.1 Presentation of themes and categories

The results of this study are reported along the themes and the categories that were derived from the qualitative data. Applicable direct quotes are supplied to substantiate relevant results.

4.8.1.1 Theme 1: Factors contributing to non-adherence to ART among the youth

Factors contributing to non-adherence to ART among the youth were one of the major themes that emerged during data analysis. Three categories appeared to relate to this theme. Data display 4.1 presents an overview of the category in this theme.

Data display 4.1 **Factors contributing to non-adherence to ART among the youth (Overview)**
4.1.1The economic burden of ART on youth was instrumental to ART non-adherence
4.1.2 Stigmatization of youths on ART
4.1.3 Lack of social support on youths on ART

Category 4.1.1: The economic burden of ART on youth was instrumental to ART non-adherence

Focus group discussion found out that those patients who were not employed had no other source of income. The study found that unemployment was a source of poor adherence. Most of the respondents lived far away from the Kangemi and Coptic Clinics and had to

walk long distances to come to the clinics as they lacked money for transport. Most felt that lack of money for transport hindered their adherence to ART.

Category 4.1.2 Stigmatization and discrimination of youths on ART

From focus group discussions, it clearly emerged that fear of the unknown might contribute to stigma and discrimination. This made some youth refuse to access health services within their immediate communities. Others collected the drugs but failed to take them when they were amidst people. They feared that people around them were going to detect their HIV status from the labels on the medicine bottle and be stigmatised.

Category 4.1.3 Lack of social support on youths on ART

From focus group discussions, it became clear that social support from a variety of sources (families, friends, organizations and their doctors and support groups) was an important factor in assisting them to adhere to their drug regimen. Majority respondents stated that care from medical personnel, families and HIV support groups were the main source of strength against the fight of stigma. One of the respondents stated the following

"A relative helps me with everything I need, when I tell them, I feel relaxed. Most of the time I just get disturbed, but all these relatives try their best, without them I would not have gone so far." A male respondent from "Kangemi slums" also stated "There is one Nurse where I work, I have told him my situation and also have informed my family, my boss and they all help me. I do also get advice and other information from my organization, 'People

living with AIDS'. Two male respondents stated "I do not have any one to consult except my doctor here, whom I will see on my date of appointment." A female respondent said "Yes, I can get assistance from both my husband and the health professionals any time I want and I am happy with that. I do not have a problem with getting assistance and support from them anytime I feel I need it." A female respondent said "Meeting with the health care provider is good; their advice gives us hope and determination to continue with HIV treatment. We normally have long sessions together, talk openly about HIV and challenges involved and we feel that we are one family brought together by God. We feel that they are also touched by our HIV hopeless situation and their approaches to our issues are human."

4.8.1.2 Theme 2: ART regimen and instructions

The second theme that emerged in the data analysis concerned ART regimen knowledge and follow-up of ART instructions. Data display 4.2 outlines the categories in this theme.

Category 4.2.1 Knowledge of ART regimen

Data display 4.2 **ART regimen and instructions (overview)**
4.2.1 Knowledge of ART regimen 4.2.2 Follow-up of ART instructions and clinically observed treatment failure. The clients explained that a simple well explained regimen was a key to success with ART.

During focus group discussions, it was noted that clients had total believe in the medical providers and their word was taken as the gospel truth. Discussion with key informant interviews demonstrated that clients who were adequately informed about ART regimen had low rates on non-adherence to ART. During the focus group discussions it emerged that antiretroviral drugs and regimens have been changed for most patients who started therapy more than three years ago and the most common reasons were due to associated side effects,

Category 4.2.2 Follow-up of ART instructions

During focus group discussions with the interviewees, it emerged that poor literacy contributed to poor adherence to ART as some could not read and understand the instructions for taking of ARVs. Some complained that the medical terms were difficult to understand. Some could not differentiate between ARVs and other medications. A female respondent asked to describe her treatments plan stated "I do not know the time limit, I think there has to be something which says, for 3 or 6 months, I do not know that, always I plan to ask but when I reach here, I get busy with other things and forgot it, but one thing I know it should not be discontinued, even exact time changed or disturbed." Though respondents did not get or have clear instruction knowledge, the benefits they obtained from the drugs and the positive relationships all had with their doctors made them stick with only what the doctors treating them said, forgetting the information they obtained from other sources.

4.8.1.3 Theme 3: Strategies for improving adherence to ART

The third theme that emerged from the data analysis concerned strategies for improving ART adherence. Data display 4.3 outlines the categories in this theme.

Data Display 4.3 **Strategies for improving adherence to ART(Overview)**
4.3.1Consider economic subsidies such as transport vouchers to patients who genuinely cannot afford transport cost.
4.3.2 Addressing stigma and discrimination against PLHA
4.3.3 Simple, clear medical instructions should be the terms of instructions to ART patients.

Category 4.3.1: Consideration of economic subsidies such as transport vouchers to patients who genuinely cannot afford transport cost.

In the focus group discussions, it was revealed that although all the respondents were receiving medicines free of charge, additional costs incurred through travel to the facilities have implications for adherence, as indicated in the following quotes from one of the respondent: *"Sir, I came from very far, over 10 kilometres from here. Before I come to the hospital I have to plan the money for journey fare to the clinic. In fact, my extra drugs got finished yesterday."* Subsidies such as transport vouchers to patients who genuinely cannot afford transport cost could improve on adherence to ART as respondents could access ARVs on time and not fail to attend to ART clinics appointment

Category 4.3.2: Addressing stigma and discrimination against PLHA

During FGD, the respondents expressed their frustrations on being stigmatised by the community due to their HIV status. Some reported that some neighbours who came to know of their status openly despised them. They experienced discrimination against them from the other patients in the clinics when being given medical service. They experienced negative attitudes of some medical workers towards them. One respondent expressed the following *"It is only through God that makes me persevere the stares and laughter from people due to my health issues"*. Fears about stigma and discrimination, even from those closest to the patient, strongly affect an individual's decisions to disclose their HIV status. The respondents were of the opinion that if the government and community in general addressed the issues of stigma and discrimination, it would improve their adherence to ART.

Category 4.3.3: Simple, clear medical instructions should be the terms of instructions to ART patients

FGD revealed that following the medical instructions for ARVs was not simple as was assumed by some medical personnel as some words were difficult to understand and was confusing on the timing of taking ARVs as morning, and evening doses were not very specific on time. Language barrier was also cited as reason of not understanding ART instructions as was written in English and some of them could not read English language. The respondents were of the opinion that if time was specified and ART instructions were written in Kiswahili would improve non-adherence to ART outcome.

CHAPTER FIVE: DISCUSSION

The main aim of the study was to identify the factors influencing non-adherence to ART among the youth in Kangemi and Coptic Health clinics in Nairobi, Kenya with a view to using these findings to improve upon the quality of care medications amongst PLWHAs. The study has shown, using routine data sources, that it is possible to use standardised methods to collect data and to measure important aspects of patient's none compliance to ART adherence. Because taking medicine is a private affair, all individual-level of non-adherence measurements are indirect. It is difficult to measure non-adherence to ART in outpatient setting with absolute precision and accuracy. While there may be no gold standard with which to measure non-adherence, non-adherence may be measured in the clinical setting by a variety of strategies such as self-reports (including surveys, interviews and diaries), clinical assessments, pill counts, directly observed therapy (DOT), prescription refills, biological assays and medication event monitoring system (Talam *et al.,* 2008;Nyambura ,2009). Most studies of non-adherence use one or more of these tools. Measuring non-adherence using patient's self-report about recent patterns of non-adherence is a low cost and commonly used method to assess non-adherence, which has correlated with clinical outcomes both in a meta-analysis (Nieuwkert *et al.*,2005) and in several resource-poor settings (Ferradine *et al.*,2006:Wools-Kaloustian *et al.*,2006). For purposes of a cross-sectional survey, exit interviews provide an opportunity to standardize the self-report question (i.e., number of doses missed in the last four days; achievement of 100% adherence). In this study, four-day self-reports recall and visual analogue scale of

patients were used as a measure of non-adherence to ART. The findings of the study showed that the overall non-adherence levels based on four-day self-report recall of taking ARVs was 5%, while by visual analogue scale was 18% ,clearly indicated that there were serious barriers to adherence. However, non-adherence was lower than other reported findings in Kenya among the adults which varied from 52% in Kibera, Nairobi (Ellis AE *et al.*, 2006); 43.2% in Eldoret (Talam NC *et al.*, 2008) and 36% in Mombasa (Munyao *et al.*, 2005). This study shows that it is possible to monitor non-adherence using the self-report recall method. This was the same method used by Talam NC *et al.*, 2008 in Eldoret. The study found that demographic characteristics such as gender did not predict non-adherence to HAART in Nairobi. These findings correlated with findings of other studies (Byakika-Tusiime *et al.*, 2005, Iliyasu *et al.*, 2005, and Talam NC *et al.*, 2008). Marital status did not predict non-adherence. Other studies have reported mixed results; Byakika *et al.*, 2005 found an association between marital status and non-adherence to ARV therapy in Uganda (Byakika-Tusiime *et al.*, 2005) while, Weiser *et al* (2003) in Botswana did not. Demographic characteristic that was found to be significantly associated with poor adherence was age ($\chi 2=11.0$, $p= 0.001$). The finding is consistent with the findings of Iliyasu *et al.,* 2005 in Nigeria but, inconsistent with the finding of Talam *et al* (2008) in Eldoret. Economic factors such as transport ($\chi 2 =8.147$, $p = 0.0001$), had significantly influenced non-adherence in this study. Findings with respect to transport costs were consistent with the findings of Kagee *et al* (2007) in South Africa, but inconsistent with the finding of Byakika *et al* (2005) in Uganda where respondents paid for their transport. Most patients who attended the health

clinics did not have private transport and they had to rely chiefly on public means, which were expensive and in some areas, unavailable. The inability to afford transport cost to the clinic contributed to poor adherence to medications. This finding of the study is supported by another study done in South Africa by Rosen *et al* (2007) that reported that South Africa was providing ART free of charge in order to increase access for poorer patients and promote adherence. However, non-drug costs of obtaining treatment might limit access. Supporting this, Kip *et al* (2009) argued that economic issues do affect ART adherence rates even if the ARVs are supplied free of charge. To estimate the costs that South African patients incur in obtaining ART, Rosen *et al* (2007) reported that patients had to visit a treatment clinic at least six times during the year in which they started ART. The average cost per visit was R120, plus travel and waiting time. Patients and caregivers also spent considerable time and money between visits. Thus, patient costs should be considered in efforts to sustain adherence and expand access.

Social-cultural factors such as Stigma ($\chi 2 = 17.991$, $p = 0.0001$), had significant influence on non-adherence to ART. Stigma as a barrier to adherence has been shown in this study to manifest itself in either subtle behaviour or overt acts of discrimination, ridicule, harassment and violence. PLWHAS often face stigma and discrimination from their community, including their own family members. Fear of stigma may force PLWHAS to conceal their HIV status even to close members of the family. The failure to disclose leads to non-adherence as the PLWHAS have to hide when taking the pills. Stigma and discrimination

associated with HIV/AIDS largely has its roots in the mode of its transmission and in the history of the epidemic. HIV is mainly a sexually transmitted infection, which first appeared among certain groups of people such as prostitutes and homosexuals, and was viewed as a disease of the immoral people (Mills *et al.*, 2006; Nyambura, 2009). The PLWHAS are thus blamed for having contracted the disease or the infection is seen as a form of punishment for the person's immoral behaviour. Not having a cure for this infection has exacerbated the situation. Therefore, anti-stigma sensitization campaigns should be enhanced and sustained so that PLWHAS could get adherence support from the family and community. This finding was supported by other studies on AIDS patients among whom 67.65% reported fear of disclosure (Mills *et al.*, 2006).

ART regimen ($\chi 2 = 20.656$, $p = 0.0001$) and follow-up of medical instructions ($\chi 2=23.732$, $p= 0.0001$) were significant to non-adherence to ART. This was consistent with a study conducted in Southwest Ethiopia, where researchers also noted that several studies have documented that inadequate knowledge about HIV disease and treatment effectiveness present important barriers to ART adherence (Amberbir, Woldemichael, Getachew, Girma & Deribe, 2008). This finding is very significant because it differs from findings in resource-rich settings where most previous adherence studies were carried out. One of such studies in a resource-rich setting showed that ability to follow-up medical instructions, gender, insurance status, and HIV risk factors were generally not associated with adherence behaviour (Volberding *et al.*, 2008).

The challenges of non-adherence to ART in resource poor settings like Kangemi slums are comparable to other non-slum areas in the world. For instance, in a study to evaluate the estimates of ART adherence in Sub-Saharan Africa and North America that included 31 studies from North America and 27 from Sub-Saharan Africa, it was found that favourable levels of adherence could be achieved in both developed and resource poor settings (Mills *et al.*, 2006).

Deciding to take steps to reduce non-adherence levels depends on available human and financial resources. One method of deciding how to reduce non- adherence to ART is to set target levels for each of the main indicators. The current results could serve as benchmarks for future surveys in other locations. Encouragingly, the two facilities surveyed are maintaining low rates of patient non-adherence to ART. However, the health facilities need systems strengthening. Using simple, low-cost methods to identify factors contributing to non-adherence to ART would allow ART program managers to examine the causes of poor performance and work with facilities to make improvements. A summary result for different indicators can point to interventions in different systems to improve facility performance. This standardized methodology and associated indicators can also be adapted to become part of an on-going monitoring system. The study made no assessment of patient retention as this was not part of the objectives. However the study recognizes the importance of the assessment of retention, as retention data collection is possible in health clinics.

This study suffers from the same weakness as many others that have evaluated adherence in Africa: It relied on self-report alone and did not compare self-report adherence to more objective measures, such as viral load and CD4 counts. It would have been very helpful to the study if respondents CD4 count and Viral Load could be estimated at least twice in an interval of at least six months to see how their non-adherence level correlates to the immunological, virological and clinical status at subsequent follow up visits. This will further validate the effectiveness of whatever non-adherence intervention they were engaged in.

Evaluating and monitoring non-adherence to ARV treatment are critical to using health care resources effectively and efficiently, reducing rates of drug resistance to first-line therapies, and improving patient outcomes. This study provides strong evidence that non-adherence evaluation is possible using routine data that can be collected systematically from a wide range of health facilities in resource-poor settings. The challenge now will be to introduce monitoring of these indicators on a routine basis and using them as the basis for facility-level quality improvement efforts.

CHAPTER SIX: CONCLUSIONS AND RECOMMENDATIONS

6.1 Overview of conclusions and recommendations

This chapter sums up the findings of the research; conclusions based on the research findings and recommendations.

6.2 Conclusions

Based on the findings of this research study, it was concluded that:

- The non-adherence according to visual analogue scale was 30% and according to four-day self-report recall was 6%.
- Demographic factors like age influenced non-adherence: the higher the age, the less levels of non-adherence of ART.
- Economic situations like lack of money for transport and unemployment significantly influenced non-adherence to ART among the youth living with HIV/AIDS.
- Social-cultural factors like Stigma, discrimination, lack of family and community support contributed to non-adherence to ART.
- ART regimen and ART instructions influenced non-adherence to ART.

6.3 Recommendations

The study recommends to the government and other stakeholders to devise strategies to encourage more youth to adhere to ART through;

- Consider social-economic subsidies such as transport vouchers to patients who genuinely cannot afford transport cost.
- Address stigma and discrimination at family, community, national and regional levels.
- Simple, clear medical instructions should be the terms of instructions to ART patients.

6.4 Suggestion for Further Research

Continuous operational research on non-adherence to ART on both rural and urban settings since non-adherence is dynamic.

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APPENDICES

APPENDIX I: CONSENT FORM

Hello, my name is Gitu Peter Martin. I am a Master of Public Health student at Kenyatta Universit Nairobi. Today I am here to carry out a study on treatment among HIV- patients.

This is a study titled "Factors that Influence Non-Adherence to Antiretroviral Therapy Among th Youth in Nairobi" by Gitu Peter Martin of Kenyatta University, Nairobi, Kenya. The purpose of th study is to gain deeper understanding of why there is suboptimal adherence to ARVs by the youth Nairobi; this will enable me to offer meaningful solution and ultimately contributing to bett services provision in reducing suboptimal ARVs adherence. In line with this, I would like to tal with you to obtain information regarding the services you received.

Please understand that you can choose to participate or not to participate in this discussion.
You are not required to tell me your name during this discussion. Staff here is also not permitted t tell me your name. I have made up a special code that I will use on this form. (SHOW FORM)
Any information you choose to share with me will be treated confidentially. That means that no only will we speak in private, but any answers you provide will remain private. Also the informatio you give us will not affect the services you receive from the facility henceforth, however we migh be able to advice you on where you can get further help if need be. If at any time you ar

uncomfortable or don't want to answer a question, just tell me, and we will stop the interview move to another question.

Do you agree to answer some questions today? No [ ] Yes [ ]

(If No) I understand that you don't want to talk with me about your experience today. Thank you for your time. (If Yes) Thank you for your willingness to talk with me. Do you have any questions before we get started?

If Yes,

Signature.....Date.....

APPENDIX II: QUANTITATIVE DATA COLLECTION TOOL
(STRUCTURED QUESTIONNAIRE)

Structured interview guide for the HIV/AIDS youth patients who are on treatment

(A) Basic Information

1. Date of interview (dd /mm/ yy)
2. Study site
3. Code of the interview

(B) Socio-Demographic Characteristics

4. Sex/ Gender of participant Male [ ] Female [ ]
5. Age in years:

1) 15 years [ ]

2) 16 years [ ]

3) 17 years [ ]

4) 18 years [ ]

5) 19 years [ ]

6) 20 years [ ]

7) 21 years [ ]

8) 22 years [ ]

9) 23 years [ ]

10) 24 years [ ]

11) 25 [ ]

6. What is your current marital status?

1).Single [ ]

2).Married [ ]

7. What is your level of education?

1).None [ ]

2).Primary education [ ]

3).Secondary education form I- IV [ ]

4).University/college education [ ]

5).Adult education [ ]

(C) Influence of social-demographic factors on adherence

8 At what age did you start taking ARVs?

1) 15 years [ ]

2) 16 years [ ]

3) 17 years [ ]

4) 18 years [ ]

5) 19 years [ ]

6) 20 years [ ]

8) 22 years [ ]

9) 23 years [ ]

10) 24 years [ ]

11) 25 years [ ]

(D) Influence of socio-economics factors on ART adherence

9. What is/was your main occupation in the last month?

1).Employed [ ]

2).Unemployed [ ]

10. Do you find the cost of transport to clinic difficult to afford? YES [ ] NO [ ]

11. Do you have a medical insurance cover that covers ART? YES [ ] NO [ ]

12.In your own opinion do you think medical insurance

Companies discriminate on people who are on ARVs when issuing

Medical cover? YES [ ] NO [ ]

(E) Proportion of HIV/AIDs patients who adhere to treatment instructions

Instructions to the study participant: Now I will ask questions relating to how you have been taking the ARV medications in the past one-month. Please be aware that everyone misses doses at some time. Be assured that this information will neither change the way you receive ARV medications from the treatment center nor your opportunity to participate in this study.

13. Have you missed any doses of HIV drugs over the last 4 days? Yes [ ] No [ ]

15. Have you missed doses of HIV drugs over the last one month? Yes [ ] No [ ]

16. kindly mark on the visual analogue scale how you have been taking ARVs

17. Do you closely follow medication dosage schedule as prescribed by the doctor?

A) All the times [ ]

B)Not at all [ ]

(F) Influence of social-cultural factors on ART adherence

Attitude/ perceptions towards ART

18. Do you avoid friends or relatives because of your illness? No [ ] Yes [ ]

19. In the last one month did you have any family or community?
    Member who supported (reminded or encouraged) you to take
    your ARV medications? No [ ] Yes [ ]

20. Is there any stigma attached to taking ARV drugs? No[ ] Yes [ ]

(G) Practice of Health Care Providers and Patients on ART

21. Are you able to follow ARV therapy regimen? No[ ] Yes [ ]

22. Were you told the importance of following medicine instructions? No [ ] Yes [ ]

24. Have you received any counselling during your treatment? No [ ] Yes [ ]

25. Do you think counselling is useful for HIV patients on treatment? No [ ] Yes [ ]

26. Was privacy maintained during consultation? No [ ] Yes [ ]

Thank you for taking time to participate in this interview

APPENDIX III: FOCUS GROUP DISCUSSION (FGD) GUIDE

I would like to inform you (participants) that your participation will be tape recorded. The information obtained will be treated in absolute confidentiality and will be used only for purpose of this study.

1. What would you say is anti-retroviral therapy?

....

2. Are there any benefits patients derive from using anti-retroviral therapy?

....

3. Is there any harm associated with stopping using ARVs? ----------

4. Everyone sometimes misses treatment doses, what do you think makes one to miss treatment doses? ----------

5. Most people, at some point, want to stop long time medication, how long do you think you will be on ARVs? ----------

6. Is it good to have privacy during consultation?

....

7. Are there problems at family level, you think hinder you from taking your treatment properly?

....

8. One needs a lot support when undergoing treatment, have you ever been supported by any one. If yes who is that person?

....

9. Are there any issues of stigmatization due to being on ART? ----------

12. Is it good to disclose ones HIV status to people around him/ her ? ----------

---

13. Everyone sometimes wants to give up on ART, what makes you to continue on ARVs? -

---

APPENDIX IV: QUALITATIVE DATA COLLECTION TOOL - (KEY INFORMATION INTERVIEW GUIDE) HEALTH CARE PROVIDER

Are you readily available at the CCC?.....

What is your own view on ARVs?.....

What are the constrains you encounter while administering ARV drugs for CCC patients?.....

In your own view does your working medical facility offer total privacy to the clients?

YES [ ]

NO [ ]

Name mechanisms that you use to follow clients who have dropped from the ART programme----------

Explain in your own words how do you a certain if the client is following prescription instructions correctly when using ARVs obtained in your CCC.----------

---

How frequent do you do stock taking for ARVs in your pharmacy? ----------

Do you usually receive your ARVs stock regularly? YES [ ] NO [ ]

Do you do home visits to clients on ARVs? YES [ ] NO [ ]

If no, in your own words explain why----------

Is your medical facility able to measure ARVs resistance? YES [ ] NO [ ]

Do you have mechanism of making sure those clients on ART to adhere to ARVs?

YES [ ] NO [ ]

Name the mechanism you use if there are any in making sure clients on ART fully adhere to ARVs?----------

In your own opinion is the personnel working in your CCC enough? YES [ ] NO [ ]

If the number of the personnel is not enough would you like to be done?

1) Increase the personnel [ ]

2) Close the CCC [ ]

3) Decrease registering clients for ART programme in your CCC [ ]

In your own view are all personnel working in your CCC programme well trained to serve in the station? YES [ ] NO [ ]

If not trained on ART what would you like be done?

1) Be transferred to other stations [ ]

2) Be trained on ART care [ ]

How many times in the course of working of the personnel in the CCC have been trained on ART care?

1) Once [ ]

2) Twice [ ]

3) Thrice [ ]

4) Not trained [ ]

Does your health facility have feedback of information about the ART care they receive?

YES [ ] NO [ ]

What would you like improved in the CCC programme?.....

APPENDIX V: OBSERVATION GUIDE

Is PLWHA's privacy respected?.....

What information is given to PLWHAs?.....

What is the waiting time at the CCC clinic?.....

APPENDIX VI: CHECKLIST MATERIALS

Name of health care facility.....

Date of interview.....

(The investigator should see the materials)

Record cards 1) available 2) not available [ ]

Record dairy 1) available 2) not Available [ ]

Counseling room 1) available 2) not Available [ ]

Have testing kits 1) available 2) not Available [ ]

Examination gloves 1) available 2) not Available [ ]

Spirit and alcohol swabs 1) available 2) not Available [ ]

Literature on CCC at the (HCF)

Leaflets 1) available 2) not Available [ ]

Booklets 1) available 2) not Available [ ]

Posters 1) available 2) not Available [ ]

Most flowcharts 1) available 2) not Available [ ]

Flip charts 1) available 2) not Available [ ]

Newsletter for clinic provider 1) available [ ] 2) not Available [ ]

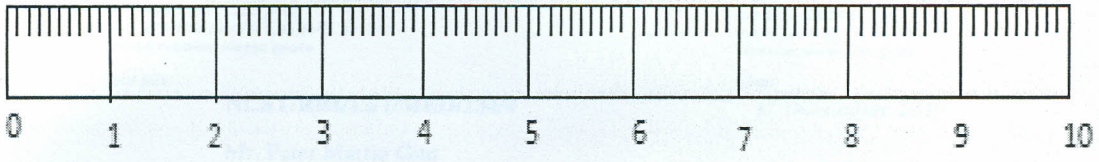
Available drugs .....

How are drugs stored?

Are they kept cool No, [ ] Yes, [ ]

Are they kept in dark No, [ ] Yes, [ ]

APPENDIX VII: VISUAL ANALOGUE SCALE



APPENDIX VIII: LETTER OF AUTHORIZATION FOR RESEARCH

REPUBLIC OF KENYA

NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

Telegrams: "SCIENCETECH", Nairobi
Telephone: 254-020-241349, 2213102
254-020-310571, 2213123,
Fax: 254-020-2213215, 318245, 318249
When replying please quote

P.O. Box 30623-00100
NAIROBI-KENYA
Website: www.ncst.go.ke

Our Ref: NCST/RRI/12/1/MED/234/4

Date: 1st December 2010

Mr. Peter Martin Gitu
Kenyatta University
P. O. Box 43844
NAIROBI

RE: RESEARCH AUTHORIZATION

Following your application for authority to carry out research on ***"Factors that influence non-adherence to Anti-retroviral Therapy among HIV infected youth in Kangemi and Coptic Clinics in Nairobi Province"*** I am pleased to inform you that you have been authorized to undertake research **in Kangemi and Coptic Health Clinics in Nairobi Province** for a period ending ***31st December 2010.***

You are advised to report to **the Provincial Commissioner and the Provincial Director of Medical Services, Nairobi Province and the Chief Executive Officer, Coptic Hospital, Nairobi** before embarking on the research project.

On completion of the research, you are expected to submit **one hard copy and one soft copy** of the research report/thesis to our office.

P. N. NYAKUNDI
FOR: SECRETARY/CEO

Copy to:
The Provincial Commissioner
Nairobi Province

The Provincial Director of Medical Services
Nairobi Province

APPENDIX IX: MAP OF THE STUDY AREA

Map of Kenya