DETERMINANTS OF ADHERENCE TO ANTI-RETROVIRAL THERAPY AND HIGH RISK BEHAVIOUR AMONG HIV INFECTED PATIENTS ON TREATMENT IN NAIROBI PROVINCE, KENYA.

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October, 2009
DECLARATION

This thesis is my original work and has not been submitted for a degree in any other university

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DEDICATION

This work first and foremost is dedicated to my beloved daughter Barbara Pauline Oyore and wife Millicent Adhiambo Oyore for their support throughout this work. Further dedication, to my beloved parents Mr. Peter B Abol Kobwanda and Mrs. Apolina Anyango Abol for sacrificing all they had to ensure I got quality education. Finally to my brother and sisters Beatrice, Emmanuel, Elizabeth, Samuel and Hannah- May you achieve even more and remember hard works pays all the time. God Bless you all.
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To everybody else who participated in making this work a success, I may not be able to quote everybody but the almighty God knows what you did to enable me succeed.

May the Good Lord bless you all!
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<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral Therapy</td>
</tr>
<tr>
<td>ARV</td>
<td>Anti Retroviral (Drugs)</td>
</tr>
<tr>
<td>CBO</td>
<td>Community Based Organization</td>
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<tr>
<td>CHW</td>
<td>Community Health Worker</td>
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<tr>
<td>FBO</td>
<td>Faith Based Organization</td>
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<tr>
<td>FGD</td>
<td>Focus Group Discussion</td>
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<tr>
<td>FHI</td>
<td>Family Health International</td>
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<td>GOK</td>
<td>Government of Kenya</td>
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<tr>
<td>HAART</td>
<td>Highly Active Antiretroviral Therapy</td>
</tr>
<tr>
<td>HCWs</td>
<td>Health Care Workers</td>
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<tr>
<td>HIV</td>
<td>Human Immuno deficiency Virus</td>
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<td>KDHS</td>
<td>Kenya Demographic and Health Survey</td>
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<tr>
<td>KII</td>
<td>Key Informant Interview</td>
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<tr>
<td>MoH</td>
<td>Ministry of Health</td>
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<td>NACC</td>
<td>National AIDS Control Council</td>
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<td>NASCOP</td>
<td>National AIDS and STDs Control Programme</td>
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<td>PEPFAR</td>
<td>Presidential Emergency Plan for HIV and AIDS Relief</td>
</tr>
<tr>
<td>PLWHA</td>
<td>People/PPersons Living With HIV and AIDS</td>
</tr>
<tr>
<td>PMTCT</td>
<td>Prevention of Mother to Child Transmission</td>
</tr>
<tr>
<td>SSA</td>
<td>Sub-Saharan Africa</td>
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<tr>
<td>SSI</td>
<td>Semi Structured Interview</td>
</tr>
<tr>
<td>Acronym</td>
<td>Full Form</td>
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<td>---------</td>
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<tr>
<td>STI</td>
<td>Sexually Transmitted Infection</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV and AIDS</td>
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<tr>
<td>UNICEF</td>
<td>United Nations Children’s Education Fund</td>
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<td>WHO</td>
<td>World Health Organization</td>
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DEFINITION OF TERMINOLOGIES AND CONCEPTS

For the purpose of this study, the following terms are defined as follows

**Optimal adherence** - Refers to adherence rate of 95% or higher, since this is the level generally deemed necessary for treatment success and to avoid the development of resistance to treatment.

**High Risk Sexual behaviour** – Refers to having sexual relations without protection with someone of unknown HIV status or multiple partners.

**Adherence to ART** Adherence is defined as the “extent to which a client’s behaviour coincides with the prescribed health care regimen as agreed through a shared decision-making process between the client and the health care provider” (Carter, 2004).

Adherence has been defined as the use of ARVs at the right frequency of dosing. The number of pills (correct dose) was also checked and the time patients were taking them, Ability to keep to this pattern of utilization is defined as 100% adherence, while adherence of ≥95% is accepted as optimal adherence. Levels of adherence below 95% are considered to be sub-optimal. A composite adherence measure was computed as the means of the optimal adherence rates of the three measures used.

**Knowledge about HIV and ART** The Oxford Dictionary, 2000 edition defines knowledge as the information, understanding and skills that is gained through education or experience. For the purpose of this study, knowledge was
assessed in terms of: what HIV is and how it can be transmitted; how ARVs work and how they should be used; whether the ARV users know that ARVs are not a cure and that they have to be taken for life. The level of knowledge was graded on a scale of 0 – 8, with a score of 75% and above depicting good knowledge.

**Side-effects**

Refers to medicine-related side-effects have been categorized according to patient/ARV user and biomedical perspectives. Where pills were missed because a patient assumed that they might be responsible for certain symptoms that are not measurable, this has been classified as a patient/ARV user perspective, while those instances where side-effects can be recorded and assessed in observable terms were regarded as a biomedical perspective.

**Disclosure**

Disclosure was deemed to have taken place if a patient on ART had shared his or her status and the fact of being on treatment with at least one friend and/or any other person (including family members) for the purpose of deriving support if needed.

**Treatment costs**

Kenya offers ARVs free of charge to any citizen who is eligible for treatment. The costs stated in this study focused on other treatment-related costs such as transport fares, foregone wages, expenditure on snacks and meals while waiting to be seen at the clinic, and increased spending on food as a result of being on ART.
<table>
<thead>
<tr>
<th><strong>Discrimination</strong></th>
<th>Denial of individuals rights to health services, freedom, self-identity, and social interactions on the basis of possession of a certain trait considered undesirable.</th>
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<tr>
<td><strong>Access to ART</strong></td>
<td>Refers to the ability to receive all the components of ART services from the designate delivery points.</td>
</tr>
<tr>
<td><strong>Service providers</strong></td>
<td>Refer to individuals and institutions certified to provide at least one component of ART services.</td>
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ABSTRACT

Anti-retroviral therapy (ART) has been successful in dramatically decreasing the morbidity and mortality caused by HIV infection. Levels of adherence in excess of 95% are required to ensure treatment success, adequate viral load suppression, improved immune status and slowing of the disease progression. It has also been reported that a lot of complacency during ART and feeling of reduced infectivity by the patients on ART could lead to high risk sexual behaviour and enhance transmission of HIV. To date there is very little scientific data on ART adherence, factors influencing it and any resultant high risk behaviour in Nairobi, Kenya. This was a non-interventional cross-sectional study using rapid appraisal techniques for collecting both qualitative and quantitative data. The main objective of this study was to determine the levels of adherence, factors influencing it and identify any resultant high-risk behavioural changes during ART among patients in selected treatment sites in Nairobi Province, Kenya. A combination of data collection tools was used to gather the information in this study including semi-structured questionnaires, adherence measurement tool and FGDs. Qualitative data was consolidated using data matrices. Analysis of qualitative data was done by triangulation based on major themes or constructs. Quantitative data was analyzed using the statistical package for social scientists (SPSS) version 16.0. Hypothesis testing was done using Chi-square and Kruskal-Wallis tests to test the significance of the categorical variables. T-tests and Mann U Whitney tests (non-parametric tests) were used to assess the differences between groups for continuous variables. Multistage sampling design was used since convenience sampling was used to determine the health facilities after which systematic sampling was used to select the patients to be interviewed. The results indicated that just about half, 216 (48%) of the PLWHA had accurate knowledge of what ARVs were and what they do to the body. There was a significant relationship between knowledge of ARVs and adherence with those having more accurate knowledge more likely to adhere ($\chi^2 = 106.432$, df = 7, $p \leq 0.001$). The composite adherence ART level of adherence from the three methods used among patients in Nairobi was found to be 85% with 43% of the patients not achieving optimal adherence. The major factors that were found to constrain adherence were costs ($\chi^2 = 306.02$, df = 7, $p \leq 0.001$), lack of social support ($\chi^2 = 0.804$, df = 7, $p \leq 0.997$), side effects ($\chi^2 = 92.583$, df = 7, $p \leq 0.00$), distance to the facility, gender ($\chi^2 = 104.006$, df = 7, $p \leq 0.02$), CD4 count at start of treatment. The results also indicated that a good proportion 342 (76%) of the patients who had been on treatment for over six months had engaged in high risk HIV transmission behaviour by either having sexual intercourse without protection or with partners of unknown HIV status. Quality of care is affected by lack of adequate supply of drugs and training of health workers. These findings will help policy intervention towards improving access and adherence to ARV through carefully planned and evaluated interventions. Furthermore, it will lead to the improvement of the quality of medication discussions and care so that both patients and care providers receive and understand the information they need, enable patients to accurately assess their readiness to initiate and adhere to ARV, identify gaps between knowledge and actual practice both for health workers and PLWHA. The information will also be given to the PLWHA to enable them reduce the high risk sexual behaviour that may predispose them to HIV re-infection. It is recommended that there should be more education and information provided to the patients prior to initiating ART so that they know the facts about ARVs. In conclusion, the study found that majority of patients on ART does not achieve optimum adherence levels and that 342 (76%) of patients on ARVs are engaging in risky sexual behaviour. The study also recommends more targeted counseling be provided by the care providers highlight the importance of adherence hence promoting adherence among the patients. There should also be improved education targeting the PLWHA to sensitize them and remind them that they are not free of HIV and AIDS even after being on treatment and that they would still get re-infected by other strains of HIV.
CHAPTER ONE: INTRODUCTION

1.1 BACKGROUND INFORMATION

We are in the third decade of HIV and AIDS which has become the most important infectious disease epidemic in the last century. UNAIDS AIDS epidemic update of July 2008, estimated that more than 33 million people worldwide are currently living with HIV and AIDS. It also states that there were 2.7 million new infections and 2.0 million deaths due HIV in the year 2007 alone. Sub-Saharan Africa is the most severely affected region with over 22 million people living with HIV and AIDS as at the end of 2007 (UNAIDS, 2008). Kenya is one of the countries hardest hit by the worldwide HIV epidemic having a population of more than 1.4 million people infected by HIV. In 2008 there were an estimated 260,000 people in Kenya living with HIV in a country with a total population of 37 million and a prevalence rate of 7.8% (UNAIDS, 2008; NASCOP, 2008).

Anti-retroviral therapy (ART) has been successful in dramatically decreasing the morbidity and mortality caused by HIV. These successes coupled with the lower-priced drugs, availability of generic drugs and an increase in donor funding has led many developing countries such as Kenya to implement and scale up HIV treatment programs for its HIV positive citizens (Pallela et al., 1998).

A major concern in scaling up the ART is the emergence of drug resistance viral strains. To prevent the emergence of such strains, optimal patient adherence to ART is necessary. Levels of adherence in excess of 95% are required to ensure treatment
success, adequate viral load suppression, improved immune status and slowing of the
disease progression (Paterson et al., 2000).

Optimism related to success of ART in slowing the disease progression, reducing
viral load and improving the health status may lead to more risky sexual practices and
a possible increase in transmission of infections. Prevention of risky sexual behaviour
among HIV positive persons on ART has therefore become an area of special interest
and concerns (Valsidieri, 2004).

1.2 STATEMENT OF THE PROBLEM

HIV and AIDS in Kenya remains one of the greatest public health challenges and has
even been declared a national disaster. In 2008 there were an estimated 260,000
people in Kenya living with HIV in a country with a total population of 37 million
and a prevalence rate of 7.8% (UNAIDS, 2008; NASCOP, 2008).

Although ART is readily available and provided free of charge in public health
facilities to patients who meet the eligibility criteria, most patients on ART still do not
comply with the strict treatment regimen. For there to be Maximum suppression of
the multiplication of the HIV virus and subsequent increase in the CD4 cell count, a
level of adherence of 95% and above in required. To date there is very little
scientific data on treatment adherence in Nairobi. Understanding the factors that
influence the adherence to aim to contribute to the implementation of strategies that
would improve the adherence rate of patients. Since the inception of the national
ART programme in Kenya, very little data has been generated to elucidate the impact
of the programmes on the sexual behaviour of the patients on ART as this could lead to a higher risk of HIV transmission and re-infection with new, drug-resistant viral strains making treatment expensive and difficult.

The quality of care given to the patients on treatment is also important in ensuring adherence and reduction of high risk behaviour among the patients.

1.3 RESEARCH QUESTIONS

a) What are the patient’s knowledge, attitude and perceptions on HIV and AIDS and ART?

b) What are the levels and factors promote or constrain adherence to ART among patients in selected treatment sites in Nairobi province?

c) What high risky sexual behavioural patterns result following the use of ART among HIV positive patients?

d) What is the quality of care given to the people living with HIV and AIDS on treatment by the health providers

1.4 RESEARCH HYPOTHESES

The study was guided by the following null hypotheses

$H_0$ -that there is no relationship between patients’ knowledge, attitude and perceptions on ART and the level of adherence

$H_0$ – that the levels of adherence to ART among patients are is not optimum

$H_0$ – That there are no factors that promote or constrain adherence to ART among patients in selected treatment sites in Nairobi province?
1.5 STUDY OBJECTIVES

1.5.1 General Objective

The general objective of the study was to determine the factors that promote or constrain ART adherence and high risk sexual behaviour that may result among HIV patients in selected treatment sites in Nairobi Province.

1.5.2 Specific objectives

The specific objectives include:

a) To determine the patient’s knowledge, attitude and perceptions on HIV and AIDS and ARVs.

b) To establish the levels and factors that promote or constrain adherence to ART among patients in Nairobi province.

c) To establish high risky sexual behaviour patterns among patients on ART.

d) To assess the quality of care given to the people living with HIV and AIDS on treatment by the health providers.

1.6 JUSTIFICATION OF THE STUDY

The consequences of low adherence are serious for the individual, public health and for the optimal use of limited health care resources. It is essential to reach and maintain therapeutic levels of these drugs and strict adherence is particularly crucial.
for preventing the development of resistance viral strain. The implications of non adherence to HAART on public heath cannot be over emphasized because choices of therapy are limited, the cost limiting and if wide spread resistance emerged treatment would be very difficult. Also the literature concerning interventions to promote adherence to ARV is remarkably scarce. It is hoped that the out come of this research will help policy intervention towards improving adherence to ARV through carefully planned and evaluated interventions. This will lead to an improvement of the quality of medication and care to enable the patients to accurately assess their readiness to initiate and adhere to ARV as well as reduce high risk behaviour that may lead to HIV transmission.

1.7 SIGNIFICANCE OF THE STUDY

Kenya supports the global “3 by 5 Initiative”, which aimed to provide ART to 3 million people in developing countries by the end of 2005. To this end, a national ART programme was developed to progressively deliver effective ART, reaching 50% of those eligible by 2005 and 75% by 2010, so as to improve the quality of life and survival of people infected and affected by HIV/AIDS

To this end, study aimed at identifying key issues which will go a long way in supporting the national strategies on HIV prevention and care by coming up with modalities of enforcing both adherence and prevention with positive. In line with the national response to the HIV and AIDS epidemic which is stipulated in the Kenya National HIV and AIDS Strategic plan (KNASP II) 2005/06 to 2009/10, the
information generated from this will be useful in addressing the following key priority areas namely:

i) Reducing new infections especially among the positive through behaviour change

ii) Improvement of the quality of life of people infected by HIV/AIDS by reducing morbidity and mortality

1.8 STUDY ASSUMPTIONS AND LIMITATIONS

The study assumed that the PLWHA in the selected treatment sites would accept to participate in the study. It also assumed that the in-charge of the facilities would grant permission for the researcher to conduct the study in their institution.

There were also some limitations to this study. For example, some of the data collection methods used in this study relied on self reports of adherence behaviour, which is prone to response biases. In addition, the study used a client sample that was currently on ART and did not include individuals who had discontinued treatment. It is also possible that some people who achieved suboptimal adherence may no longer be visiting the treatment facilities.

Second, the financial resources for the study were limited hence the study only involved a convenient sample in selected treatment sites. Although convenience samples may not be used to generalize to larger populations, the findings revealed
important insights into adherence and sexual behaviour among HIV-infected populations receiving treatment through Public and private health facilitates.

Finally, it may not be possible to relate the obtained adherence rate to viral loads and CD4 cell responses due to financial and logistical barriers to frequent laboratory monitoring in this study. However, the combination of different approaches and respondents permitted extensive triangulation and give a comprehensive set of results in spite of the various problems faced.

1.9 THEORETICAL AND CONCEPTUAL FRAMEWORK

1.9.1 Theoretical framework

The theoretical framework used in this thesis was adapted from the Health Belief Model as developed by Rosenstock in 1966 and modified by Beckar in 1974. It has been used to predict preventive health behaviour, such as screening and compliance with medical advice (Naidoo & Willis, 2003). The model was used as a framework to develop the research objectives and the research questions of this study. The literature review is also based on this model. The model was also used to guide the development of data collection instruments, the research findings and conclusions.

The health belief model is a commonly used framework in health behaviour change. As much as the health belief model is patient oriented, health care providers such as physicians also need to understand and use it as a tool to help promote behaviour change in patients. The health belief model is an appropriate theoretical framework to use to explore the behaviour of patient’s adherence to antiretroviral treatment. The
health belief model can also provide useful intervention for physicians in their attempts to make informed judgements about measuring the success of patient adherence to ART. The health belief model presented below provides information that can be used to analyze factors that contribute to patients’ perceived state of health and to predict patients’ adherence patterns.

Figure 2.1 illustrates how the Health Belief Model by Janz et al 2002 is applied to this study.
Figure 1.1: Adapted Health Belief Model

Physicians’ beliefs and perceptions about HIV

Physician’s perception of:
- Patient’s perceived susceptibility to and severity of AIDS; of HIV disease; of ART; of adherence and of the patient’s belief in treatment efficacy

Factors impacting on adherence cost, geographical factors, nature of treatment regimen, health worker factors, social habits & lifestyles, stigmatization, socio demographic factors, migration

Patient’s perceived threat of non-adherence to treatment

Cues to action
- Patient involvement, communication and information, education, simplified treatment regimen, directly observed treatment, political commitment, infrastructure & support systems

Patient’s likelihood of behaviour change

ADHERENCE TO ART

Patient’s perceived benefits minus perceived barriers to behaviour change

Patient’s likelihood to adhere

Modifying factors

Adapted from Becker 1974; Source: Naidoo & Willis, 2003
1.9.1.1 Perceptions and beliefs on health and disease

Physicians act as primary medical care providers to people with HIV and AIDS and physicians’ attitudes, perceptions and beliefs towards HIV and AIDS are of utmost significance in the effective delivery of health care (Duyan et al., 2001). One major factor that influences patients’ adherence to ART include the patients’ own perceptions of their susceptibility to and severity of progressing to AIDS and the patient’s own belief in the treatment. These perceptions influence the patients’ behaviour to treatment.

1.9.1.2 Patient’s perceived susceptibility

According to the health belief model, patients’ beliefs about their perceived susceptibility do influence a patient’s effort to change health behaviour (Ulin et al., 2005). If the patient perceives his/her health as very important, he/she would adhere to treatment. This will also assist the patient to understand their susceptibility to resistant strains of HIV and progression to AIDS. This information on a patient’s susceptibility should be imparted to the patient. Physicians need to personalize the risk of non-adherence based on a person’s characteristic behaviour (perceived susceptibility) (Janz et al., 2002).

1.9.1.3 Patient’s perceived severity

The implications of failure to adhere (perceived severity) to treatment such as treatment failure, immunologic failure, rapid progression to AIDS and death should be made clear to the patient by the physician (Janz et al., 2002:48). According to the
health belief model, the seriousness of a condition influences a patient’s effort to change to better health behaviour (Ulin et al., 2005). Perceived severity to non-adherence is based to a great extent on the patient’s knowledge about HIV and AIDS.

1.9.1.4 Patient’s perceived belief in treatment efficacy

According to the health belief model, the patients’ belief in the diagnosis and the therapy also does influence adherence. If patients do not believe in the treatment plan, they may not adhere to treatment as prescribed by the physician. If patients are in denial that they are infected with HIV, they will not find it necessary to take therapy.

1.9.1.5 Modifying factors

Modifying factors in the health belief model include factors that are modifiable and have some effect on patients’ adherence to ART. These include the factors impacting on adherence and the cues to action that can be implemented to promote adherence. Some of the factors are described below

a) Cost factors

The health belief model hypothesizes financial cost as a modifying factor that has some influence on a patient’s ability to change and maintain a health-related behaviour. The patients’ contribution to their treatment costs might have an impact on adherence.

b) Geographical factors
The adapted health belief model addresses distance as a probable modifying factor that has some influence to an individual’s health behaviour change (adherence). Some of the reasons cited as difficulties for patients to adhere to treatment included the need to be absent from work, leaving work to keep clinic appointments and the need to travel long distances to the clinic. Some patients lived far away from the clinics.

c) **Health workers related factors**
Health workers related factors constitute another set of modifying factor that have been identified as having an impact on a patient’s adherence to ART. The way patients were treated the last time they used health services could have some influence on their willingness to go back to the same place for service. If the physicians have insufficient time to assess patients’ needs or concerns it might affect ART. Some physicians may also avoid discussing adherence with their patients because of uncertainty about how to discuss ART adherence with their patients.

d) **Social habits and lifestyles**
Active alcohol consumption, drug use and unstable housing may be associated with poor adherence to ART.

e) **Stigmatization**
The threat of social stigma may prevent people living with HIV from disclosing their HIV status. This may serve as a barrier to ART adherence.

f) **Socio demographic factors**
The original health belief model addresses demography as a factor that may affect an individual’s perception and consequent health-related behaviours. It emphasizes socio-demographic factors, particularly education attainment, as having some indirect effect on health behaviour. Lower educational achievement and lower income are each independently associated with lower adherence. Lower income would mean failure to buy food, thus resulting in difficulty to take treatment on an empty stomach.

**g) Migration**

The adapted health belief model addresses migration as one of the factors impacting on the patient’s adherence habits. Traveling away from home may lead to a patient missing a dose.

**h) Cues to action**

The health belief model addresses the ‘cues to action’ that motivate the decision-making processing (self-efficacy) about executing the target behaviour (adherence). In this model the cues to action that promote adherence include patient involvement, communication and sharing of information between patient and physician, simplification and individualization of treatment regimens and support strategies that include directly observed therapy, the political commitment, the infrastructure and support systems of the country.

1.9.1.6 Patients’ likelihood to adhere

Underlying the health belief model is the theory of adherence as a function of perceived benefits minus perceived barriers to adherence. The likelihood of patients
adhering to treatment is high if the perceived barriers by the patients are less than the perceived benefits. The way patients perceive HIV and AIDS and the ART, the effect of the modifying factors that impact on adherence and the modifiable cues to action implemented by the physicians would determine the patient’s likelihood to behaviour change. If the benefits of adhering are perceived to be more than the barriers, patients would adhere to ART.

The patients’ understanding on the effects of not adhering to treatment would contribute to the patients’ behaviour change. The combined levels of susceptibility and severity of the disease should energize the patient to act (to adhere). In order to improve patients’ adherence behaviour and to plan on the cues to action, physicians need to understand the underlying concepts of the health belief model.

**Summary of the Theoretical Framework**

ART is a life-long therapy and patients are bound to experience pill fatigue. Regular assessment of patients’ adherence to therapy for optimal treatment outcome is necessary. Adherence to ART is important as it has been shown to lead to reduced morbidity and mortality caused by HIV disease, increased immunologic response and the suppression of viral load and hence an improved quality of life of HIV infected people. The biggest concern of non adherence is the emergence of drug resistant strains, the use of complex and expensive regimens, and the rapid progression of HIV disease to AIDS. An adherence rate close to 100% is recommended for effective outcomes of ART. The predicted adherence rate for Botswana was 74% adherence if cost were to be removed as a barrier. Assessment methods include patients’ self-
report, pill count, electronic monitoring and pharmacy-based approaches and biological markers such as the plasma concentration of antiretroviral drugs.

A health belief model has been used to explain the modifying factors that would influence a patient to adhere to treatment. For behaviour change to succeed, people must feel threatened by the consequences of non-adherence (perceived susceptibility and severity) and believe that adherence to ART will result in an acceptable outcome.

1.9.2 CONCEPTUAL FRAMEWORK

The conceptual framework on below identifies the service factors, patient factors and socio-economic and cultural factors leading directly or indirectly to access and sub-optimal adherence to ARVs.
Figure 1.2 CONCEPTUAL FRAMEWORK ON THE FACTORS THAT PROMOTE OR CONSTRAIN ADHERENCE

**SERVICE FACTORS**

- Low accessibility to services

**PATIENT FACTORS**

- Lack of knowledge and information
- Side-effects
- Pill burden

**SOCIO-ECONOMIC AND CULTURAL FACTORS**

- Poor services support
  - Long waiting time
  - Inadequately trained health workers
  - Treatment guidelines not available
  - Poor medicines supply system
  - Insufficient infrastructure
- Beliefs and patients preference for traditional medicine
- Treatment guidelines not available
- Poor medicines supply system
- Insufficient infrastructure
- Perception of causes and transmission of HIV
- Poor social support
- Stigma
- Lack of employer support
- Occupation
- Mobility
- Long distance to the health facility

**ART SUB-OPTIMAL ADHERENCE**

Source: Adapted and Modified from Weiser et al 2003
CHAPTER TWO: LITERATURE REVIEW

2.1 INTRODUCTION

This chapter deals with the literature associated with ART adherence and high risk behaviour among people living with HIV. Adherence to antiretroviral therapy (ART) is well recognized to be an essential component of individual and programmatic treatment success. Higher levels of adherence are associated with improved virological and clinical outcome. Near perfect pill taking (Values exceeding 95%) are desirable in order to maximize the benefits of ART (Weiser et al 2003). This means taking the correct dose of drugs at the right times and observing any dietary restrictions. Anything less than this leads rapidly to the development of viral resistance and hence to much earlier treatment failure. Missing even only one tablet in a week translates to only 92.8% adherence (Republic of Kenya, 2004).

2.2 ART AND CURRENT REGIMENS IN KENYA

Antiretroviral drugs act by blocking the action of enzymes that are important for the replication and functioning of HIV. Once HIV invades a host cell macrophage or T-lymphocyte, the enzyme HIV “reverse transcriptase” initiates the process of copying the viral genome code (Ribbonucleic Acid) into the infected host cells (Dioxyribonucleic acid). Following this process, HIV genetic material is integrated into the host’s DNA. The virus is then replicated, creating several billion new copies of HIV per day. The enzyme “protease” contributes to viral replication by enabling the assembly and release of viable particles of HIV from infected host cells.
Currently available ARV drugs belong to two major classes:

1. Reverse Transcriptase Inhibitors (RTIs), which block the action of the HIV reverse transcriptase enzyme
2. Protease Inhibitors (PIs), which block the action of the HIV protease enzyme

The RTIs are further divided into two groups namely
a) Nucleoside Reverse Transcriptase Inhibitors (NRTIs)
b) Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs)

In most Kenya a range of ARV drugs have been approved, licensed and registered for the treatment of HIV. The table below summarizes the list of the current ARV regimens currently available in Kenya.

Table 3.1 List of approved ARV drugs

<table>
<thead>
<tr>
<th>Class</th>
<th>Drugs</th>
</tr>
</thead>
<tbody>
<tr>
<td>NRTIs</td>
<td>Zidovudine (ZDV)</td>
</tr>
<tr>
<td></td>
<td>Didanosine (ddl)</td>
</tr>
<tr>
<td></td>
<td>Zalcitabine (ddC)</td>
</tr>
<tr>
<td></td>
<td>Stavudine (d4T)</td>
</tr>
<tr>
<td></td>
<td>Lamivudine (3TC)</td>
</tr>
<tr>
<td></td>
<td>Abacavir (ABC)</td>
</tr>
<tr>
<td></td>
<td>Tenofovir (TDF)</td>
</tr>
<tr>
<td>NNRTIs</td>
<td>Nevirapine (NVP)</td>
</tr>
<tr>
<td></td>
<td>Efavirenz (EFV)</td>
</tr>
<tr>
<td></td>
<td>Delavirdine (DLV)</td>
</tr>
<tr>
<td>PIs</td>
<td>Saquinavir (SQV)</td>
</tr>
<tr>
<td></td>
<td>Ritonavir (RTV)</td>
</tr>
<tr>
<td></td>
<td>Indinavir (IDV)</td>
</tr>
<tr>
<td></td>
<td>Nelfinavir (NFV)</td>
</tr>
<tr>
<td></td>
<td>Amprenavir (APV)</td>
</tr>
<tr>
<td></td>
<td>Lopinavir/ritonavir (LPV/r)</td>
</tr>
</tbody>
</table>
2.3 SIDE EFFECTS OF ART AMONG PATIENTS

Anti-retroviral drugs may have varied side effects on the patients. Some of the major side effects are described below.

a) Diarrhoea

Diarrhoea is a common side effect of many antiretroviral drugs – especially protease inhibitors. Other possible causes include HIV, other infections and antibiotics. Sometimes an antiretroviral drug causes diarrhoea for only the first few weeks; in other cases this side effect lasts for as long as the drug is taken.

The severity of diarrhoea also varies. While even occasional attacks may be inconvenient and embarrassing, persistent diarrhoea can also lead to dehydration, poor absorption of nutrients and drugs, weight loss and fatigue.

Drinking plenty of fluids and replacing electrolytes will reduce the risk of dehydration. Electrolytes – such as potassium, sodium and magnesium ions – are essential to health and are depleted by diarrhoea. Ways of replacing electrolytes include oral rehydration salts (available from pharmacies), sports rehydration drinks (such as Gatorade or Powerade, though the high sugar may worsen diarrhoea), diluted fruit juices, soups, and homemade rehydration mixtures (8 level teaspoons of sugar and 1 level teaspoon of table salt per litre of water). Eating bananas, potatoes, fish or chicken will help to replace potassium.

Source: Safe and Effective Use of ARV Treatments in Adults, WHO(2008).
Over-the-counter medicines such as Imodium (loperamide), Lomotil (diphenoxylate and atropine) and calcium supplements are sometimes all that is needed to control diarrhoea. If these fail then doctors can prescribe stronger treatments, which may have to be injected. Sometimes nothing works, and changing drugs may be the best option (WHO, 2008).

b) Nausea and vomiting
Almost all antiretroviral drugs, as well as many other medications, can cause nausea (feeling sick) and vomiting, especially during the first few weeks of treatment. Although this side effect can reduce appetite, it is important to keep eating when possible, and to replace lost fluids and electrolytes.

Some antiretroviral drugs can be taken with food, and doing so may lessen their harmful effects. It may also be possible to alter drug dosage or frequency. Various treatments, known as anti-emetics, are available for nausea and vomiting, some of which do not require a prescription. There is some evidence that ginger and peppermint may help against nausea. If nausea and vomiting are severe, or occur with other symptoms such as dizziness, thirst, fever, muscle pain, diarrhoea, headache or jaundice, then this may indicate a more serious problem such as lactic acidosis or pancreatitis. In this case medical attention should be sought as soon as possible (WHO, 2008).
c) Rash

Rashes often appear as a side effect of antiretroviral treatment. These may be itchy but are usually harmless and short-lived. However, severe rashes can occur with nevirapine, and more rarely with some other drugs. Any rash occurring during the first few weeks of treatment should be reported to a doctor immediately, as should any rash accompanied by fever, blistering, facial swelling or aches. Antihistamine tablets can soothe rashes and are generally available without a prescription. However, because these may interact with antiretroviral medications, patients should check with their doctors before using them. More severe skin problems may be treated with steroids (WHO, 2008).

d) Lipodystrophy

Lipodystrophy involves losing or gaining body fat, often in ways that can be disfiguring and stigmatising. Although lipodystrophy sometimes affects people with HIV who have not taken any antiretroviral drugs, it occurs more often among those receiving treatment. The condition is among the most common long-term side effects of combinations of drugs from the NRTI and protease inhibitor classes. It is particularly associated with stavudine, and to a lesser extent zidovudine. The precise causes of lipodystrophy remain unknown. The treatments for lipodystrophy are sadly limited. Changing diet seems to make no significant difference, though resistance exercise (such as weight lifting) may improve the appearance of limbs by building muscle to compensate for lost fat. Any form of exercise will burn fat, which may
make some parts of the body look better and others worse, depending on how fat has been redistributed. Aerobic exercise (such as running or swimming) tends to have more effect on the fat just below the skin than on the deep fat gained through lipodystrophy. Switching antiretroviral treatment should stop the symptoms getting worse, but is unlikely to lead to much improvement once the condition has advanced (WHO, 2008).

e) Lipid abnormalities and the heart

Lipid abnormalities are another common side effect of some antiretroviral drugs – particularly protease inhibitors – and are often seen in people who also have lipodystrophy. Lipids are molecules of fat, cholesterol and related chemicals that have important roles in the body. Many factors including diet, smoking and exercise can affect the balance of these chemicals in the blood. Abnormal lipid levels can be harmful to health. HIV positive people taking antiretroviral treatment commonly have high levels of a lipid called LDL cholesterol, low levels of HDL cholesterol, and high levels of triglyceride in the blood. Among HIV negative people such lipid abnormalities have been linked to greater risks of heart disease, stroke and diabetes (WHO, 2008).

2.4 IMPORTANCE OF ADHERENCE TO ART

Since 1996, an overwhelming amount of evidence from clinical trials has been published validating the use of ART for the treatment of AIDS. The biological
and clinical goals of treatment have been defined as the suppression of viral replication, restoration of the immune response, a halt in the progression of disease, increased survival rates, reduced morbidity and a better quality of life. In countries where access to this level of care is available, AIDS-related mortality and morbidity have significantly declined (Pallela et al., 1998).

Maximum and sustainable suppression of HIV viral replication to below the level of detection is necessary to achieve these biological and clinical goals. To achieve success requires near-perfect adherence to combination ARV regimens. Adherence to an ARV treatment regimen involves taking all pills in the correctly prescribed doses, at the right time, and in the right way (Carter, 2005). It involves taking all the medicines which make up the ARV combination in the correct quantities, taking the pills at the right times. Taking the medication at the wrong time can cause a rise in viral load and this may lead to the development of drug resistance.

It also includes ensuring that the medication is taken with or without food, according to the instructions. Some medicines need to be taken with food to ensure that the body absorbs them properly while others need to be taken on an empty stomach, a certain amount of time before or after eating. It can also be important that the patient eats the right kind of food; for example, the amount of fat eaten can make a difference to how well some drugs are absorbed.

Finally it includes checking for interactions with any other medication or drugs. This includes medicines that have been prescribed for the patient, or bought at a
pharmacy, supermarket or health store, including complementary or alternative therapies. Some recreational and illegal drugs can have potentially dangerous interactions with ARVs.

The best response to ART is seen when adherence is 100%. Levels of adherence below 95% have been associated with poor suppression of HIV viral load and a lower increase in CD4 count (Carter, 2005). It means if a patient is taking once -daily treatment, 95% adherence means missing no more than one dose a month. If a patient is taking treatment twice a day, 95% adherence means missing no more than three doses a month and if a patient is taking treatment three times a day, 95% adherence means missing no more than four doses a month.

However, many people with AIDS do not manage to achieve such high levels of adherence. Failure to suppress viral replication completely inevitably leads to the selection of drug -resistant strains, limiting the effectiveness of therapy. Sub -optimal adherence to ART is the strongest predictor of failure to achieve viral suppression below the level of detection and most often underlies treatment failure. Evidence suggests that greater than 95% adherence may be necessary to adequately suppress viral replication, produce a durable response and halt disease progression (Paterson et al., 1999). This means that missing more than one dose of a regimen per week may be enough to cause treatment failure. In addition to leading to disease progression this may result in the development and transmission of drug -resistant viruses which cannot be treated with first -
line (lower cost) medicines. This requires treatment with second - and/or third -line medicines, which are more expensive, associated with many side -effects and are complex to manage.

The challenge of adherence in the face of potential viral resistance, treatment failure, disease progression and the spread of drug -resistant virus to sexual partners are of great concern. Patients on long -term ART with undetectable levels of HIV still harbour replication -competent virus ( Furtado et al., 1999). For this reason, with current medications, ART is a life -long process. While conscientious treatment adherence is difficult under any circumstances, the unforgiving nature of HIV replication, the complexity of the ART regimens, and the associated short - and long -term toxicity of the medicines all pose particularly difficult challenges for patients.

It should be recognized that adherence to ART is a critical issue, and it is clear from the literature that the factors that influence a patient ’s ability to adhere are multiple and complex. A multitude of variables such as income, education and marital status have all been shown to affect adherence to ART, to differing degrees. In addition, some studies of ART in developing countries show that resistance is already circulating among patients starting their first "official " course of therapy that is when somebody has acknowledged their HIV status, is willing to speak about it freely, and is seeking treatment from an accredited site for proper monitoring and follow -up) Before ART was scaled up, fear of stigma led many people to seek ARVs clandestinely on the black
market. As a result, people sometimes took medicines on the basis of instructions from the person selling them on the black market and use of ARVs was poorly monitored (Mugyenyi, 2002).

2.5 MEASUREMENT OF ADHERENCE

Researchers involved in the measurement of adherence have realized that there is no gold standard by which it can be quantified (Farmer, 1999). The many methods employed by the different studies include: pill counting, electronic drug monitoring (EDM), pharmacy refill records, biochemical markers and other self-reporting techniques such as visual analogue and recall methods. The relative accuracy of adherence measures ranks from physician assessment and self-assessment being the least accurate, to pill counting being intermediate, and EDM being the most accurate (Gill et al., 2005).

Electronic drug monitoring more accurately predicts undetectable viral load (UDVL) than self-report or pill count. Its main advantages are that it provides data on the timing of doses taken and permits monitoring over long periods. Since adherence can be known precisely, the link between adherence levels and UDVL can be established with a high degree of confidence. Arnsten et al., (2001) noted that patients whose EDM data indicated high adherence (above 90%) were far more likely to achieve UDVL than patients self-reporting the same level of adherence. Other studies have reported similar results on the relationship between UDVL and EDM-rated
adherence: Paterson et al (2000) observed UDVL in 80% of those with above 95% adherence, while in a trial conducted by Kirkland et al (2002) mean adherence was 94% with 85% of the patients achieving UDVL. However, no single measure is appropriate for all settings or outcomes. It has been found that the use of more than one measure of adherence allows the strengths of one method to compensate for the weakness of the other and to more accurately capture the information needed to determine adherence levels (Vitolins et al., 2000).

Studies in African settings have indicated optimal adherence rates (the proportion of patients who adhered to their ART schedule at least 95% of the time) ranging from 54% to 98% depending on the measure used: Botswana (Weiser et al. 2003); Nigeria (Daniels, 2004); South Africa (Ferris et al, 2004 Darder et al, 2004); Uganda (Byakika Tusime, 2003: Munganzi, 2004); and Rwanda (Omes, 2004).

2.6 FACTORS AFFECTING ADHERENCE TO ART
2.6.1 Demographic characteristics

Although the literature consistently demonstrates that demographic characteristics are not strong predictors of adherence, some correlates of adherence are described below together with socioeconomic factors. Age may influence adherence. Studies have found that, with the exception of the most elderly, adherence increases with age. In two studies associated with ART adherence, sub-optimal adherence showed a positive correlation with being younger (Jones et
al., 1999). A lower level of general education and poorer literacy may impact negatively on some patients’ ability to adhere, while a higher level of education has a positive impact (Catz et al., 1999).

Studies conducted in Africa reveal that the cost of medication is one of the most significant barriers to ART adherence. In Botswana, Weiser et al., (2003) reports adherence difficulties related to the financial demands of therapy and an inability to afford medicines for varying periods. They noted that 70% of patients claimed that the cost of ARVs posed a problem for them, and 44% of patients believed that the cost impeded their ability to adhere to treatment. Similarly, over one-half of health care providers (56%) believed that financial problems often or always impeded adherence to ART. The extent to which financial difficulties played a key role in sub-optimal adherence is also reported in study findings in Uganda for patients receiving non-subsidized therapy (Byakika-Tusiime et al., 2003).

Medications and clinic visits cost money and may stretch an already meagre budget. In resource-poor countries many people live below the poverty line and there is often no medical insurance or disability pension for people living with HIV (PLWHA) (Katabira, 2002).

2.6.2 Lack of support
Living alone and a lack of support have been associated with an increase in sub-optimal adherence (Williams and Friedland, 1997), and social isolation is predictive of sub-optimal adherence. Not living alone, having a partner, social or
family support, peer interaction, and better physical interactions and relationships are characteristics of patients who achieve optimal adherence (Motashari et al., 1998).

2.6.3 Side effects
Almost all of those who are currently on ART are on a regimen of three or more ARVs (Grierson et al., 2000). The likelihood of a patient’s adherence to a given regimen declines with polypharmacy, the frequency of dosing, the frequency and severity of side-effects, and the complexity of the regimen (Williams and Friedland, 1997). Drug hypersensitivity is common in patients with HIV and regimen-associated toxicity is a common predictor of, and reason for sub-optimal adherence, which has been identified across many studies. Side-effects associated with each individual ARV medicine have been well documented and, while not universal for every patient, can be predicted. Although these side-effects usually subside after the first few weeks of therapy, for some people they persist. The anticipation and fear of side-effects also have an impact on adherence. Poor adherence has also been associated with patients’ desire to avoid embarrassing side-effects (like sweating) in certain situations such as on a date or at a job interview (Burgos et al., 1998).

Lack of symptoms (despite laboratory evidence of the need for ART) may have an adverse effect on adherence (Jones et al., 1999). Most patients with untreated HIV infection has a median AIDS-free time of 11 years, and ART is often
begun when patients have laboratory evidence of disease progression but are essentially asymptomatic and feeling well. In Kenya, the policy is to initiate treatment in patients with documented HIV infection and have met WHO Stage IV disease, irrespective of CD4 cell count; or Advanced WHO Stage III disease, including persistent or recurrent oral thrush and invasive bacterial infections, irrespective of CD4 cell count or total lymphocyte count. Another consideration is that the patients with a CD4 cell count of 200/mm³ or less for patients in WHO Stage I, II or III of having Tuberculosis with a CD4 cell count of 200-350/mm³.

Depression and severe anxiety are both predictors of sub-optimal adherence (Hirschorn et al., 1998). At some time in the course of their illness, most people with HIV, experience a psychiatric disorder (Buhrich and Judd, 1997). Depression and/or anxiety are reported in up to 70% of AIDS patients with symptomatic disease. Adherent patients demonstrate significantly less depression or other psychiatric disturbance (Catz et al., 1999).

As the disease progresses, HIV may have an impact on the central nervous system and affect memory. AIDS-related dementia (AIDS Dementia Complex) is a common finding in patients with advanced disease and is characterized by abnormalities in cognitive and motor functions. Although studies describing adherence and AIDS Dementia Complex were not found, cognitive deficits have a negative impact on adherence to ART (Meisler et al., 1993). Even when cognition is unimpaired, it is difficult to remember when to take medications.
2.6.4 Patients knowledge and beliefs on HIV and ART

A patient’s beliefs about their illness and the effectiveness of medication are predictive of adherence. A good level of understanding about HIV by the patient, a belief that ART is effective and prolongs life, and recognition that poor adherence may result in viral resistance and treatment failure (Wenger et al., 1999) all impact favourably upon a patient’s ability to adhere. Conversely, a lack of interest in becoming knowledgeable about HIV and a belief that ART may in fact cause harm adversely affect adherence.

2.6.5 Distance to the clinic

The effect that the clinic setting has on adherence should not be underestimated. Clinic characteristics that impact on adherence include: proximity to the patient’s home or place of work, the expense of getting there, lengthy delays between appointments, clinic opening and closing times, long waiting times, lack of services such as child care, privacy, confidentiality, and unsympathetic or inconsiderate staff (Nemecheck and Tritle, 1998).

Obtaining a prescription during a clinic visit is reported as an obstacle to adherence. In some developing countries, just over 50% of ARV users are given a prescription which lasts for three months, 40% receive a prescription for one month and 12% for two months (Burgos et al., 1998). In addition, some dispensing pharmacies only dispensed one month’s medication at a time (often on a single designated clinic day) and not all pharmacies are able to dispense
ARVs. As a result of such difficulties in prescription procedures, some patients attend their local pharmacy for most prescription medicine and another separate pharmacy for their ARVs. This is a barrier to optimum adherence in that problems in obtaining or taking medicines have to wait until the designated clinic day, by which time patients may already be defaulting on their dose (Grierson et al., 2000).

2.7 THE POTENTIAL FOR INCREASED RISK BEHAVIOUR

Experience in industrialized countries indicates that it is possible for the potential benefits of ART to be overwhelmed by complacency about the threat of HIV thus resulting to an increase in risk behaviour and new HIV infections (Vasidieri, 2004; Stolte, 2004).

Increases in risk behaviour may occur for a variety of reasons, including a belief by some that HIV is no longer as serious and the perception that HIV -positive people on ART are no longer infectious. People may also have difficulty adhering to a lifetime of safer sexual behaviour (Kalichman et al 1998). In addition, ART significantly enhances quality of life and personal sense of well being, enabling many individuals to resume sexual activity- which may involve risky behaviour. While this can be an important benefit of the therapy it could also increase opportunities for HIV transmission (Valasco-Hernandez et al., 2002).

It is too early to know whether increases in risk behaviour seen in industrialized countries surfaced in developing countries as ART is introduced. Past evidence from
Kenya suggests, however, that perceived treatment advances may have had an impact on levels of risk behaviour (JHA et al., 2001, Otieno BA (2008)).

Since 1985, surveys have detected notable increases in condom use among commercial sex workers in Kenya. Evidence indicates, however, that the upward trajectory of condom use was twice interrupted when highly touted anti-HIV therapies attracted significant public interest. In 1988–90, when press reports in Africa suggested that the drug Kemron was a cure for aids, reported condom use plummeted (JHA et al., 2001). Again, in 1993–94, when an agent called Pearl Omega generated comparable press coverage as a possible treatment for HIV, reported rates of condom use sharply declined (JHA et al., 2001). To ensure that increased risk behaviour does not over-whelm the natural prevention benefits of ART, it is vital that ART be coupled with a simultaneous expansion of prevention strategies that have been shown to reduce the risk of HIV transmission.

CHAPTER THREE: MATERIALS AND METHODS

3.1 STUDY DESIGN AND APPROACH

A descriptive, cross-sectional, correlation design was used to examine the relationship between the patients’ level of ART adherence and High risk behaviour and the various factors which may influence it. The purpose of descriptive designs is to observe, describe and document aspects of a situation as it naturally occurs in a given population. Cross-sectional designs are conducted in the present time to examine what currently exists and they are fundamentally characterised by the fact that all data are collected at one time (Brink & Wood 1998). Correlational design is used when the
investigator has reason to suspect a relationship between variables and can support this suspicion from literature or previous research. Brink and Wood (1998) give the following additional assumptions for correlation design: the variables have not been shown to co-vary in previous studies of similar populations; and there is no tested theory on which to predict the possible relationships between the variables. These variables exist in the population and they were studied as they exist naturally without manipulation. The factors were studied as they exist in the population without any manipulation. The method used for selecting and estimating the sample made it representative.

3.2 VARIABLES

3.2.1 Independent Variables

The independent variables to this study comprised socio-demographic characteristics of the PLWA such as age, gender, education level, current income, occupation, depression levels, family characteristics, support strategies. The variables were each analyzed vis-à-vis whether or not the patients had achieved optimum adherence level with the aim of finding out if there was any relationship with the adherence.

3.2.2 Dependent variables

The dependent variables of interest in the study were the level of adherence to ART which was measured and compared to the internationally agreed standard of 95% adherence level required for the best outcome of the treatment. Another dependent variable was the engagement of the patients on high risk behaviour. High risk behaviour was described as having unprotected sexual intercourse with a person
whose HIV status is not known to you or who is HIV positive. Having multiple sexual partners was also considered as high risk sexual behaviour.
3.3 STUDY AREA

Figure 3.1 Map of Nairobi showing the administrative divisions
3.3.1 Location and history of Nairobi City

Nairobi city was founded in 1889. Since its foundation as a railway camp in 1899, Nairobi has grown to become the largest city in Kenya, and one of the largest cities in Africa. Nairobi is the capital city of Kenya a status that was handed to it from Mombasa in 1905. It is also the capital of the Nairobi Province and of the Nairobi District.

Nairobi is located on $1^\circ 17'0''S, 36^\circ 49'0''E$. The city lies on the Nairobi River, in the south of the nation and has an elevation of 1661 m (5450 ft) above sea-level. Nairobi has the highest urban population in East Africa, estimated at between 3 and 4 million. According to the 1999 Census, in the administrative area of Nairobi, 2,143,254 inhabitants lived within 684 km² (NCC, 2006). Administratively it is subdivided into eight constituencies including Makadara, Kamukunji, Starehe, Langata, Dagoretti, Westlands, Kasarani and Embakasi.

3.3.2 Justification of study area

Nairobi a cosmopolitan city with varied cross-cultural and socio-economic characteristics that enriched the study results. This enables the researcher to make comparisons of the individuals, interpersonal and environmental factors influencing adherence. Nairobi has a HIV prevalence of about 10% (NACC, 2006). Nairobi province also has very many health facilities that are offering ART to PLWHA. The study was done at various treatment sites which were grouped as either public or private facilities.
3.4 TARGET POPULATION AND SAMPLE SIZE DETERMINATION

3.4.1 Target Population

The study targeted all ART users (that is, PLWHA) in Nairobi Province, health care professionals involved in the provision and supervision of ART and members of PLWHA support groups.

3.4.2 The Study Population

3.4.2.1 Inclusion criteria:

(a) Patients

   i. The patients included in the study were those aged 18 years or over and willing to participate in the study

   ii. The patients must have been on ART for a period of at least six months to enable the assessment of adherence to the drugs.

(b) Health care workers

   i. The staff included must have been working at the ART clinic and also willing to participate in the study

   ii. They must also have been those who deal directly with the patients on ART.

3.4.2.2 Exclusion criteria

(a) Patients

   i. The patients who were not willing to be interviewed were excluded from the study.

   ii. Any patient below the age of 18 years were not included in the study
(b) Health care workers

i. The health care workers who were not willing to be interviewed and had worked at the ART clinic for less than one month were also not interviewed.

ii. Those not directly interacting with ARV patients were excluded from the study as well.

3.4.3 Sampling technique and sample size determination

A registry file from each facility’s reception was used as a sampling frame from which ARV users was selected for the study, using systematic sampling. Various data collection techniques were employed in this study. This was done to avoid bias in the sample. The sampling was done on a proportionate to size design whereby a proportion of the registered patients were asked to participate in the study. The table below shows the number of patients interviewed from the various facilities.

Table 3.1: Outline of selected treatment facilities where the study was conducted

<table>
<thead>
<tr>
<th>Name of facility</th>
<th>Category of facility</th>
<th>Number of patients interviewed</th>
<th>Proportion of the total sample (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kenyatta national Hospital</td>
<td>Public hospital</td>
<td>99</td>
<td>22</td>
</tr>
<tr>
<td>Mbagathi District Hospital</td>
<td>Public Hospital</td>
<td>65</td>
<td>15</td>
</tr>
<tr>
<td>Pumwani maternity Hospital</td>
<td>Public hospital</td>
<td>65</td>
<td>15</td>
</tr>
<tr>
<td>St Mary’s Mission Hospital</td>
<td>Private Hospital (Mission)</td>
<td>63</td>
<td>14</td>
</tr>
<tr>
<td>Coptic hospital</td>
<td>Private Hospital (Mission)</td>
<td>45</td>
<td>10</td>
</tr>
<tr>
<td>Family health options Kenya</td>
<td>Private Hospital (NGO)</td>
<td>69</td>
<td>15</td>
</tr>
</tbody>
</table>
The desired sample size for simple random sampling was obtained from a formulae as used by Lemeshow et al., (1990) thus:

\[ n = \frac{z^2 p(1-p)}{d^2} \]

**Where**

- \( n \) Desired sample size
- \( z \) Critical value of the Confidence Interval for a standard normal distribution (for 95% Confidence Interval, \( Z=2.272 \) (one tailed ))
- \( p \) Proportion of the population estimated to have the desired characteristics (Percentage of those in need of ART receiving it in Kenya as at May 2007= 35 %)
- \( d \) Required precision = 0.05

Therefore,

\[ n = \frac{2.272^2 \times 0.35 \times 0.65}{0.05^2} \]

\[ = 469 \]

In addition to this, a total of (six) 6 health workers were also interviewed at each of the (seven)7. They were of different professions and cadres and included at least a
Doctor/Clinical officer, Nurse, Pharmacist/Pharmacy technologist, laboratory personnel, Counsellor and a Nutritionist.

Due to some limitations in the study, which were occasioned by post election violence which affected some patients in Kibera, who were attending St. Mary’s Mission Hospital. I was able to interview 450 which is a response rate of 96%.

3.5  **Pilot Study**

The questionnaires were pretested at Thika District Hospital. It was done to ensure that tools test what they are intended to (validity) and that they consistently measure the variables in the study (reliability). Pre-testing was done to test for difficulty in understanding the questions and the respondents were encouraged to ask any questions about items they are not clear about. Unclear items were reviewed, reconstructed and adjustments made to the final questionnaire. Any important corrections, clarifications, suggestions and omissions highlighted during the pre-testing exercises will be used to improve the final instrument.

3.6  **RESEARCH INSTRUMENTS**

A combination of data collection tools were used to gather the information in this study. Tools used for data collection from ARV users was semi-structured questionnaires, adherence tool, observation guides and FGDs.

3.6.1  **Semi structured questionnaire**

A total of 450 self administered semi structured questionnaires (Appendix 1) were given to ARV users. The questionnaires were designed to enable investigation of
personal experiences of ART from the respondent’s point of view. They were helpful in assessing the quality of care and also served as a back-up to the FGD findings. They were also used for measuring adherence to ART using two methods i.e 2 day recall based on a chart and pill count.

### 3.6.2 Focus group discussions

Focus group discussions (appendix 2) were conducted with patients organized by age and sex who were enrolled at the selected sites. The aim was to identify factors influencing access and adherence by people on ART. Each FGD comprised of 8 to 12 participants.

A total of 8 FGDS were conducted (3 with males and 5 with females). The FGDs were used to determine the knowledge, beliefs, attitudes and behaviour in relation to the use of ARVs; investigate social support given to PLWHA; and to get suggestions on ways of improving adherence to ARVs. The moderator had an FGD guide, use it to keep the research focused on the main themes of the study. The location was considered when selecting participants for the FGDs (i.e. public hospitals, private hospitals and Mission hospitals). The FGDs focused on getting the views of community leaders and other opinion leaders on the use of ARVs as well as the community’s perception of and solutions to the problem. At each facility the counselor helped to identify participants for the discussion.

### 3.6.3 Observation guide

The researcher conducted non-obtrusive three observations on doctors/nurses, pharmacists, counselors/social workers and receptionists at each facility. The
aim was to explore aspects such as interactions between clients and service providers in health facilities, the availability of ARV stocks, stigmatizing behaviour and the length of time spent at the facility, privacy, and organizational procedures. Observational notes were then used to foster triangulation during data analysis and discussions.

3.6.4 Adherence measurement tool

The instruments used to measure adherence were:

i. Two-day recall, involving the use of 'sun and moon' charts to measure the consistency of the times respondents took their medicine over the previous two days.

ii. Pill count method undertaken by the dispensing pharmacist, in which the numerator was the number of pills supposed to have been taken over a given period minus the number of pills missed and the denominator was the total number of pills supposed to have been taken.

iii. Health workers’ assessment, comprising the estimate of the level of adherence to treatment by ART clients over a period of not less than three months.

3.6.5 Key informant interview guide

A key informant interview was administered to health care workers in the selected health care facilities. The health professionals who were interviewed included Medical doctors or clinical officers, nurses, counselors, laboratory personnel, nutritionist, and pharmacy staff. In this regard a total of 40 health care staff were
interviewed with the aim of getting information on the quality of care that was being provided to the ART users and their perception on adherence issues.

3.7 DATA MANAGEMENT AND ANALYSIS

Data checking and cleaning were done simultaneously during data collection. At the end of every field day, data was checked for completeness and consistency, and FGDs transcribed. All relevant sources of data were considered to allow for triangulation. After transcribing and cleaning, quantitative data was analyzed using the Statistical Package for Social Scientists (SPSS) and EPI info. Hypothesis testing was done using Chi-square test. Independent predictors of lower adherence were determined using logistical regression analysis. A p value of <0.05 was considered significant.

3.8 Ethical Considerations

The main ethical issues observed and considered in this study are as follows:

i) Participants had a right to take part in the study and research or not

ii) The research was carried out with minimum risk to respondents.

iii) Participants were provided with adequate information on the research before the interview, and because of the level of literacy, consent obtained was mainly verbal (oral).

iv) Anonymity and confidentiality were ensured

v) Scientific accountability was observed as much as possible through proper cross-referencing and by listing all sources used at the end of this thesis.

vi) Authority to conduct the research was obtained from Kenyatta University Graduate School and Ministry of Education, Science and Technology (see
3.9 RELIABILITY AND VALIDITY

3.9.1 Validity

3.9.1.1 Internal validity

The following approaches were selected to increase internal validity: the use of random sampling techniques; the homogeneity of the selected group (see population criteria); and blocking of some of the possible extraneous variables, such as the demographic characteristics, by including and measuring them.

3.9.1.2 External validity

In this study, efforts to enhance external validity included the random selection of a large sample, which made it more representative, and the comparison of the findings with other previous studies found in the literature.

3.9.1.2 Reliability

Reliability refers to the accuracy and consistency of information obtained in a study and the term is most associated with the methods used to measure research variables. In this study, the use of a standardised interview protocol for all respondents increased the consistency of the information collected.
CHAPTER 4 - RESULTS

4.0 INTRODUCTION
This section presents the results obtained from the various tools that were employed to collect both quantitative and quantitative data. The quantitative data were collected using an adherence survey tool and semi-structured interviews; the qualitative data on the other hand were collected using Focused Group Discussions and observations guides.

4.1 SOCIO-DEMOGRAPHIC CHARACTERISTICS OF THE RESPONDENTS

4.1.1 Distribution of the participants based on age
Twenty eight percent of the respondents were aged between 30-35 years of age with the lowest percentage being from the age group 18-25 years (11%) as shown in Figure 4.1. Indeed, this distribution is consistent with the general trends in HIV rates where the most hit population comprises of the young adults within the age bracket of 18 to 40 years.

Figure 4.1 Distribution of respondents by age (n=450)
4.1.2 Distribution of Respondents by gender
Figure 4.2 below indicates that the majority of the respondents were females (62%) while males comprised of 38%. The results indicated that there were more females on ARVs compared to the males.

![Pie chart showing distribution of respondents by gender](image)

Figure 4.2 Distribution of the Respondents by Gender (n=450)

4.1.3 Distribution of respondents by education level
The results of the study indicated that majority (51%) of the respondents who were on ARVs had attained at least college or university level of education. The results are indicated in Figure 4.3 (on the next page). The highest educational level seemed to have influenced their awareness and decision to undertake ARVs.
Figure 4.3 Distribution of the respondents by educational level (n=450)

4.1.4 Distribution of respondents based on the marital status

The results indicated that the majority (53%) of the respondents were those currently married followed by those who were never married accounting for 38%, the least being those who separated/divorced (9%), as shown in Figure 4.4. Being in marriage seemed to be an encouraging influence to undertake ARVs.

Figure 4.4 Distribution of respondents by marital status
4.2 KNOWLEDGE, ATTITUDES, BELIEFS AND PRACTICES RELATING TO ANTI-RETROVIRAL THERAPY

4.2.1 Reasons for deciding to take a HIV test

The analysis of results in Figure 4.5 below indicated that a relatively high percentage of the respondents (53%) got to know their status while undergoing treatment. Other reasons that made the people living with HIV and AIDS to seek to know their status were partners being diagnosed positive (15%), expectant mothers undergoing PMTCT (14%) and 3% were traveling and this forced them to test. Finally, 12% specifically went to check for their HIV status. This shows that a very small percentage took the decision to do HIV testing; implying that there is still very low uptake of VCT.

![Figure 4.5 Distribution of respondents based on reasons for HIV test](image-url)
4.2.2 Distribution of respondents based on the duration since diagnosis

The results indicated that a majority of them 256 (57%) had been diagnosed more than two years before the time of the interview (Figure 4.6). The others had been diagnosed less than 6 months earlier 64 (14%), six months to one year ago 50 (11%) and between one to two years ago 80 (18%). The Figure below shows the distribution of the respondent based on the duration since diagnosis.

![Figure 4.6 Distribution of respondents by the duration since diagnosis](image)

4.2.3 Disclosure of HIV test results

The patients were asked whom they shared their test results and the results indicated that 36% shared the results of the test with their relatives, 30% with their spouses, and 20% with their friends. Only 14% did not share their HIV test results with anyone. In essence, there was a high probability of sharing HIV test results with close relatives than any other person.
Disclosure was significantly associated with a regular partner’s HIV status. Respondents with a HIV positive partner were significantly more likely to report disclosure of their HIV status compared to respondents with an HIV-negative partner or respondents with a partner of unknown HIV status. The lowest disclosure rates were observed with partners of unknown HIV status. However, even though a significant number of respondents believed that disclosing to relatives and friends had the potential to improve adherence, some of them also perceived that disclosure carried a number of risks such as: emotional injury, loss of intimate relationships and job loss.

![Bar chart showing percentage distribution of respondents based on whom they disclosed their HIV test results.]

**Figure 4.7** Distribution of the respondents based on whom they disclosed their HIV test results
4.2.4 Knowledge of HIV and ARVs

The participants were asked about what they knew about ARVs and whether they thought ARVs would cure for HIV or not. The knowledge about HIV and ARVs was rated using eight questions worth one point each. Forty-eight per cent of the participants got a score of at least 75%. For the purpose of evaluating the impact of knowledge on adherence, a cutoff of 75% was used (>75% good knowledge). The results indicated that of the patients who were taking the drugs only 47.1% accurately knew what ARVs were with majority (52.9%) not knowing what it was based on the cut off.

Table 4.1: A comparison of the relationship between level of Knowledge of ARVs and whether or not the patients achieved optimum adherence level

<table>
<thead>
<tr>
<th></th>
<th>Less than optimum adherence (below 95%)</th>
<th>Optimum adherence level (above 95%)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adequate knowledge of ARVs</td>
<td>55 (25.5)*</td>
<td>161 (74.5)</td>
<td>216</td>
</tr>
<tr>
<td>Inadequate knowledge of ARVs</td>
<td>183 (78.2)</td>
<td>51 (21.8)</td>
<td>234</td>
</tr>
<tr>
<td>Total</td>
<td>238 (52.9)</td>
<td>212 (47.1)</td>
<td>450</td>
</tr>
</tbody>
</table>

*Numerals in parenthesis refer to proportions expressed in percentages

4.2.5 Experience of the side effects of ARVS

The respondents were asked if they had experienced any side effects of using ARVs and the results indicated that majority of the respondents (85%) had experienced some side effects with only 13% stating they had not experienced any side effects. \( \chi^2 = 244.689, \text{df } = 1, \ p \leq 0.04 \). The results indicated that there was a significant relationship between the experiencing side effects of ARVs and adherence. It showed that majority of the respondents who had experienced some side effects were less
likely to adhere to the treatment since they took some time dealing with the side effects. This results concur with those found by Burgos et al., (1998), who also found out that the existence of side effects is likely to influence adherence levels. The results are shown in Figure 4.8 and table 4.2.

![Figure 4.8 Distribution of respondents based on whether or not they had side effects of ARVs](image)

<table>
<thead>
<tr>
<th>Experienced side effects</th>
<th>Adherence level</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sub Optimal</td>
</tr>
<tr>
<td>Yes</td>
<td>172 (81%)</td>
</tr>
<tr>
<td>No</td>
<td>41 (19%)</td>
</tr>
<tr>
<td>Total</td>
<td>213</td>
</tr>
</tbody>
</table>

Table 4.2 Relationship between adherence level and experiencing of side effects
4.2.6 How the patients had felt since beginning treatment
The patients were asked whether in their opinion they had felt some improvement in
the quality of their health since they started treatment. The results showed that
majority 423 (94%) of the respondents had felt better while a small proportion of
27(6%) had not got any improvement and were feeling the same. This results show
that the majority of the patients already had a reduction of opportunistic infections.

4.2.7 Use of other medicines in combination with the ARVs
The study participants were asked if they were using any other drugs in combination
with the ARVs that they were given from the hospital. The results indicated that most
of the (70%) were not using other drugs. It was however noted that a small proportion
of 30% were using others drugs which could affect the outcome of the medication.
The use of other drugs was found to interfere with adherence with most of the patients
using failing to adhere.

4.2.8 Sources of the other drugs used in combination with the ARVs
Of the patients who admitted to be using other drugs in addition to the ARVs, they
were asked to state the sources of drugs they were using. The results indicated that
about 30% were using herbs obtained from herbalists and another 70% obtained the
drugs from chemists. The other drugs from the chemists were mainly pain-killers.

4.2.9 Disclosure that one is taking ARVs
The results indicated that for the many of the respondents (35%) disclosed to their
spouses that they were taking ARVs. Others whom they disclosed the information on
taking ARVs included the siblings (25%), parents (14%) and friends (9%). It is also
worth noting that 17% of the PLWHA had never informed anyone they were on taking ARVs. Figure 4.9 shows the results of disclosure that one is taking ARVs.

![Figure 4.9: Distribution of Respondents based on whom they disclosed to that they are on ARVs](image)

4.2.10 Duration since started taking ARVs treatment
The respondents were asked to state the duration they had been on treatment. The results indicated that majority of them (41%) had been on treatment for more than 24 months. Figure 4.10 illustrates the results as per duration in which the respondents had been on ARV treatment.
4.2.11 Patients missing any medication since beginning treatment

The respondents were asked if they had ever missed any medication since they started taking the drugs. The results indicated that 44% of the respondents had missed some medication, while slightly high percentage (45%) of the respondents had not missed any of the medication, as shown in Figure 4.11 below.
Figure 4.11 Distribution of respondents on whether or not they have missed medication

4.2.12 Reasons for missing medication by the patients

The 44% of patients who had missed some medication were then asked to state whether they had missed medication for any of the reasons stated in the table below. They were allowed to have multiple responses on the reasons stated. The Table 4.3 below gives a summary of some of the reasons stated for having missed medication.

Table 4.3: Reasons for missing medication (n=198)

<table>
<thead>
<tr>
<th>Reasons for missing medication</th>
<th>Proportion who missed due to this reason (%)</th>
<th>Proportion who did not miss due to this reason (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The clinic was not accessible</td>
<td>20(10)*</td>
<td>178(90)</td>
</tr>
<tr>
<td>Did not have food</td>
<td>30(15)</td>
<td>168(85)</td>
</tr>
<tr>
<td>Pill burden</td>
<td>26(13)</td>
<td>172(87)</td>
</tr>
<tr>
<td>Lack of care and support</td>
<td>67(34)</td>
<td>131(66)</td>
</tr>
<tr>
<td>Was depressed</td>
<td>26(13)</td>
<td>172(87)</td>
</tr>
<tr>
<td>The distance to the facility</td>
<td>24(12)</td>
<td>174(88)</td>
</tr>
<tr>
<td>Alcohol use</td>
<td>14(7)</td>
<td>184(93)</td>
</tr>
<tr>
<td>Did not have the pills with me</td>
<td>19(10)</td>
<td>179(90)</td>
</tr>
<tr>
<td>Had to hide medication</td>
<td>50(25)</td>
<td>148(75)</td>
</tr>
</tbody>
</table>

*Numerals in parenthesis refer to proportions expressed in percentages
4.2.13 Change of the treatment regimen

The respondents were asked if they have ever had to change treatment since they started medication. The results indicated that about 45% had at least changed treatment regimen. They were further asked to state some of the reasons that may have made them to change the treatment regimen. The results indicated that majority (58%) had changed the medication because of side effects. Another 25% of the respondents changed the treatment because the drugs were not available while 17% changed the treatment due to treatment failure. The figure 4.12 below shows a summary of the results.

![Figure 4.12 Reasons for changing treatment regimens](image-url)

Figure 4.12 Reasons for changing treatment regimens
4.3 LEVELS OF ADHERENCE TO ART AMONG PATIENTS ON TREATMENT

4.3.1 Proportion of patients who achieved optimum adherence levels

The results indicated that about 39% of the people living with HIV and AIDS did not achieve optimum adherence level for ARVs using the self reporting method while by use of the pill count method it was realized that 43% failed to achieve optimum adherence to the ARVs. Figure 4.13 shows the proportion of patients who were adhering to treatment.

![Figure 4.13 Level of adherence to ARV treatment by method of measuring used](image)
4.3.2 ART Adherence level among respondents

Various methods were used to measure the level of adherence among patients to ART. The optimal adherence rates (at least 95%) using the pharmacy pill count, self report (visual line) and self report (two day recall method) were estimated to be 84%, 77% and 96% respectively. The composite mean adherence level was estimated at 85%. This means that a good proportion of the participants did not achieve optimum adherence which is necessary for the treatment to be effective. Figure 4.14 below show the level of adherence among patients by various methods used.

Figure 4.14: Distribution based on the level of adherence among patients by various methods used.
4.4 FACTORS THAT PROMOTE OR CONSTRAIN ADHERENCE TO ART

4.4.1 Duration taken by the respondents to reach the health facility

The participants were asked to estimate in time how much time they took by public means to travel from home to the health facility. The results indicated that majority (35%) took between 30min to 1 hour to get to the facility. The others took less than 30 minutes (28%), 1-2 hours (16%) and more than 2 hours (19%). This showed that a significant number of patients took a long period of time to get to the facility ($\chi^2 = 40.276$, df=3, $p\leq 0.07$). The duration taken to the health facility was found to effect on the level of adherence. Table 4.3 below shows the results of the relationship between duration taken to travel to hospital and adherence level.

<table>
<thead>
<tr>
<th>Duration</th>
<th>Below optimum</th>
<th>Optimum</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 30 min</td>
<td>0 (0%)</td>
<td>80 (33%)</td>
<td>80 (26%)</td>
</tr>
<tr>
<td>30 min – 1 hour</td>
<td>28 (44%)</td>
<td>108 (44%)</td>
<td>136 (44%)</td>
</tr>
<tr>
<td>1 – 2 hours</td>
<td>11 (17%)</td>
<td>39 (16%)</td>
<td>50 (16%)</td>
</tr>
<tr>
<td>More than 2 hours</td>
<td>14 (22%)</td>
<td>26 (11%)</td>
<td>40 (14%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>63 (21%)</strong></td>
<td><strong>243 (79%)</strong></td>
<td><strong>306 (100%)</strong></td>
</tr>
</tbody>
</table>
The results when cross tabulated indicated that the duration taken to the health facility influence the level of adherence, with 92% of those who achieved optimum adherence level having to travel only 1 hour or less to the health facility.

### 4.4.2 Cost of traveling to the health facility

The respondents were asked to state how much money they used to travel to the health facility. The costs were computed for a round trip. The results indicated that there was a wide discrepancy in the amount of money that they spent based on the mode of transport used. The lowest amount spent was Ksh 20 and the highest amount of money spent was Ksh 500. The mean amount of money spent on transport was Ksh. 170.60. The median was Ksh. 140, mode Ksh. 100 and the standard deviation was Ksh. 110. Figure 4.15 shows the distribution of respondents by traveling expenses.

![Distribution of respondents by traveling expenses](image.png)

Figure 4.15 shows the distribution of respondents by traveling expenses.
4.4.3 Ways of remembering to take the pills

The patients were asked to state some of the ways that they had used to enable them remember to take pills. The most common method that had been used to remember when to take the pills was the cell phone or clock (42%). 7%, were reminded by their friends, 12% by relatives, 30% linked it to meal times and 8% were just conscious that they need to take the drugs at particular times. Figure 4.16 shows the distribution based on the various ways of remembering to take pills.

![Figure 4.16 Ways used by the patients to remember to take drugs](image-url)
4.5 HIV HIGH RISK TRANSMISSION BEHAVIOURS AMONG PATIENTS ON ART

The study in an attempt to identify the HIV transmission risk behaviour among the PLWHAs explored the sexual behaviour of respondents and their relationships with regular partners and casual partners within the last six months. The Male respondents were also asked about sexual activity with sex workers. The key themes of analysis were type of partners, knowledge of partner status, disclosure of own HIV status to partners, condom use at last sex, and consistent condom use.

4.5.1 Having sexual intercourse in the past six months

The respondents were asked whether they had engaged in sexual intercourse in the last six months. The findings showed that 76% had sex in the last six months, as shown in Figure 4.17 below.

![Figure 4.17 Engagement in sex in the last six months](image)

4.5.2 CD4 Count at the start of ART

The data from the CD4 count at the start of the ART was obtained for all the patients from the register. The results indicated that 44% of the patients started ART when the CD4 count was less than 100 cell/mm3, 37% started the treatment with a CD4 cell
count of between 101 to 200 cells/mm3 with only 18% starting ART with a CD4 cell count of more than 200 cells/mm3 as shown in Figure 4.18 below.

**Figure 4.18 CD4 cell count at the start of ART**

4.5.3 Disease stage at the start of ART and sexual activity

The Disease stage at the start of ART, based on CD4 counts, was found to be associated with reported sexual activity, since patients who had initiated ART with advanced HIV disease (CD4 cell counts $< 100$ cells/mm 3) were significantly less likely to report sexual activity in the past six months compared to respondents who had initiated ART with higher CD4 cell counts ($P \leq 0.037$). This is because the patients who started the treatment with lower CD4 cell count may have experienced many episodes of opportunistic infections.
4.5.4 The type of sexual partner with whom they had sex
Ninety-three (93%) percent of respondents who indicated being sexually active in the past six months also indicated having sexual intercourse with a regular partner. Only five (5%) percent of respondents reported having had sexual intercourse with a casual partner and two percent with a sex worker. All the respondents who reported sex with a casual partner or a sex worker were male.

4.5.5 Knowledge of the HIV status of the partners at the time of sexual intercourse
Because the majority of respondents reported sexual activity with a regular partner, these relationships were explored in greater detail. The Partner status reported here is based on patient report since HIV testing was not conducted. Respondents were asked whether or not they knew the HIV status of their regular partner. Overall 83 percent of respondents who reported sex with a regular partner reported knowing their partner’s HIV status. Forty-three percent reported an HIV-positive partner, 40 percent an HIV-negative partner, and 17 percent reported not knowing their partner’s HIV status. Statistically significant differences were seen between men and women.

4.5.6 Use of condom during the last sexual intercourse
The respondents who had engaged in sexual intercourse were then asked whether they had used a condom in the last sexual encounter. The results indicated that only 27% had used a condom in the last sexual encounter. A huge proportion of over 72% however did not use a condom during the last encounter. These results also concur with those of a study by JHA (2001) who stated that the rates of condom use decline in PLWHA after some time.
4.5.7 Condom use with a regular partner

Eighty-nine percent of respondents used a condom the last time they had sexual intercourse with their regular partner. Ninety-eight percent of respondents who reported having had sex with a regular partner during the reference period were married.

A higher proportion of male respondents reported condom use during their last sexual experience with a regular partner compared to female respondents (90 percent versus 82 percent), but the difference was not statistically significant. Condom use was not found to be associated with time since diagnosis of HIV (testing positive for HIV), disease stage (defined by CD4 cell counts at start of ART), or time on ART.

Respondents with lower levels of education reported significantly lower condom use compared to those with higher levels of education. Condom use was more common with an HIV-negative partner. Ninety-six percent of respondents with an HIV-negative partner reported using a condom at last intercourse compared to 83 percent with a HIV positive partner and 87 percent with a partner of unknown HIV status.

Patients who reported not using a condom at last intercourse with their regular partner were asked to give reasons for that. Having an HIV-positive partner was the most frequently cited reason, followed by dislike of condoms and lack of awareness of the importance of condom use by HIV-positive persons as shown on Table 4.4 on the next page.
Table 4.4 Reasons stated by respondents for not using a condom (n=324)

<table>
<thead>
<tr>
<th>Reason for not using a condom</th>
<th>Frequency</th>
<th>Proportion mentioned %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Partner is HIV-positive</td>
<td>74</td>
<td>23</td>
</tr>
<tr>
<td>Don’t like using condoms</td>
<td>36</td>
<td>11</td>
</tr>
<tr>
<td>Did not know about using condoms for this disease</td>
<td>36</td>
<td>11</td>
</tr>
<tr>
<td>Did not feel the need to use condoms</td>
<td>36</td>
<td>11</td>
</tr>
<tr>
<td>Found it difficult to discuss condoms</td>
<td>36</td>
<td>11</td>
</tr>
<tr>
<td>Did not have condoms at hand</td>
<td>23</td>
<td>7</td>
</tr>
<tr>
<td>Has never used condoms before</td>
<td>23</td>
<td>7</td>
</tr>
<tr>
<td>Not disclosed status to partner</td>
<td>11</td>
<td>3.5</td>
</tr>
<tr>
<td>Condoms take away romance from sex</td>
<td>11</td>
<td>3.5</td>
</tr>
<tr>
<td>Would make partner suspicious</td>
<td>11</td>
<td>3.5</td>
</tr>
<tr>
<td>Condoms are difficult to use</td>
<td>11</td>
<td>3.5</td>
</tr>
<tr>
<td>Total</td>
<td>324</td>
<td>100</td>
</tr>
</tbody>
</table>

4.5.8 Respondents intending to get married after starting ARVs

The 171 respondents who were not married at the time of the study were asked whether they were intending to get married given that they were HIV positive. The results indicated that (89) 52% were intending to get married while (82) 48% did not see any need for getting married. Of the respondents who wanted to get married, 58% were females while 42% were males. The results also indicated that most (91%) of the respondents who wanted to get married were below the age of 35 years while only 9% who wanted to get married after knowing their status were aged above 35 years. On education level, majority (91%) of those who wanted to get married had at least secondary education with only 9% having no formal education or primary level of education.
4.5.9 Respondents intending to have children

The respondents were then asked whether they were intending to get children now that they were HIV positive. The aim was to find out if they still would have wished to have any more children especially after knowing that they were suffering from a terminal illness. The results indicated that 40% of them wanted to have children while 60% did not want to have children.
4.6 RESULTS FROM FOCUS GROUP DISCUSSIONS

This section focuses on the findings from the qualitative data on the determinants of adherence to ART among adult patients at the health facilities in Nairobi province. These data are based on the perspectives of patients on ART and health care workers.

4.6.1 Constraints to adherence to ART

In the discussions on determinants of adherence, the study identified six interrelated themes. These are presented below, without any order of priority.

4.6.1.1. Gender and non-acceptance of HIV status

Gender was identified as being strongly associated with acceptance of HIV status. Respondents stated that women talk about HIV and test early, and so are more likely to accept their status than men. Men were said to avoid testing for HIV. But when their partners test first, they often blame them for bringing the virus. As a result, men can become angry and violent and tell the partner not to bring the medication into the (‘his’) home.

In Pumwani, there were stories of women who were hiding their ARVs in a neighbour’s house for fear that their husband would discover that they were still taking the pills. This interfered with adherence in that most of the time these female participants would be dependent on their neighbour’s schedule for access to their medication. Female participant were also reported to avoid telling their partners about their HIV positive status in order to protect the relationship. This results in re-infection and in the hiding of drugs.
Most respondents agreed that individual acceptance of positive HIV status is key to the behavioural changes that are required for a good health outcome. Non-acceptance of positive HIV status and of lifelong dependency on ART for survival were perceived by many respondents as a major barrier to adherence. A female ARV user put it succinctly:

“In life people feel shy to tell others about their status and that they are on ARVs. People do not advise them because they do not know they are on treatment. When one has a visitor, he/she will start skipping treatment. They end up dying because they fail to take the drugs.”

When an ARV user is in a state of denial, it is difficult to disclose to others, medicines are hidden from friends and relatives, and when necessary they skip medication to ensure that friends and family do not discover that they are HIV positive. A male ARV user explained:

“I usually miss my medications when I visit friends because I have not told them about my HIV and so I do not want them to see my medications.”

Meanwhile, a female ARV participant expressed the following:

“My boyfriend did not tell me his status and was against me going to test for HIV saying that it was not we had not been unfaithful and could not be sick
because I was pregnant. As a result he hid his ARVs from me. He kept all the other medications on the dressing table but one time when I was cleaning, I saw some bottles of medications hidden away. I wrote the names on the paper and went and asked the nurse about them. She told me they were ARVS. I went back and asked him why he did not tell me. I think he wanted me and the baby to die because he did not want us to get help by testing.”

Many respondents thought that women were more likely to accept their HIV status than men and that woman generally have better health seeking behaviour than men. Some women consider the better health seeking behaviour of women to be due to their desire to stay alive in order to care for their children and other loved ones, despite being blamed by men for the disease.

Health care workers attributed the greater acceptance of positive HIV status by women and their better health seeking behaviour to the fact that women have always been very close to the health care system through the maternal and child clinics.

One ARV user in a female FGD explained:

“Women accept their status easily; we chat and get encouragement from other people. We like to know our HIV status even while still young without having children; we would like to know so that we may help others.”

Another female ARV user said:
“Men are stubborn. I had a partner and we had a child who later passed away. I tested and my husband accepted me but he refused to test himself. I wonder why he refused.”

One of the men said:

“Men are brave, strong. We believe in our tradition/culture. It is not easy for us to go and consult the doctor. Men believe in herbs but the disease doesn’t tolerate that.”

Respondents generally agreed that acceptance of status could result in increased disclosure and possibly in improved adherence.

4.6.1.2 Non-disclosure that one is HIV positive or taking ARVs

Nondisclosure was one of the themes that emerged as a barrier to adherence. Respondents stated that failure to tell someone (e.g. a friend or family member) is due to reasons such as: fear of being discriminated against, stigma, job loss or abandonment. It was not uncommon to hear of people who were rejected by their partners because they had revealed their HIV status. This problem is highlighted by the following quotes from an FGD involving female ARV users:

“Those on treatment at times do not tell their partners.”

“Some women hide their status fearing to be dumped by their partners after disclosing their HIV status.”
“A man will leave you if you tell him.”

Male participants, on the other hand, complained that women do not disclose their status in order to keep them in the relationship. One of them noted that:

“Those who get pregnant while on treatment might not have told their partner...”

The male respondents also maintained that no man would refuse to use a condom if they knew that the woman was HIV positive. Meanwhile, young adults who were in relationships also found it difficult to disclose their status, because they are tested independently and do not necessarily know the status of their partner. One ARV user explained:

“For us the unmarried youth, you will find that even when you know your status, it is not easy to disclose because you do not know your partner’s status. You end up hiding medications because when you tell them, they disappear after a short period. We usually weigh the situation because we would not want our names to be spoiled”

4.6.1.3 Perceived lack of social support, fears about stigma and privacy concerns

The participants also discussed issues relating to lack of social support, fears about stigma and privacy concerns that acted as constraints to adherence. These issues are presented under the following three levels: individual, family/friends, and workplace.
a) **Individual level**

Some respondents identified the personality traits of the individual as being important in determining how they perceive stigma, privacy issues, and the availability of social support. Lack of self motivation was said to result in low adherence. People who lack self motivation are less likely to disclose their status and therefore less likely to attract social support. And even where social support is available, there may be a tendency not to use it. This was supported by a female respondent who said:

“My younger brother who was on treatment refused to take his ARVs, and even to talk to the social workers visiting at home. He never did well and ultimately die.”

Some respondents perceived the partial integration of ART with other health services as exposing them to the likelihood of being stigmatized, as one ARV user at a semi-integrated health care facility explained:

“We will like to have our own clinic instead of being mixed with these other people. They are always staring at us, especially when we come to this door (labelled “ARV Dispensary”). I like it in Hospitals where ARV users are isolated from the rest of the people. Some people fail to come and refill here because they are shy to be seen by their friends.”
b) Family/friends

Family social support and acceptance of a relative or friend living with HIV and AIDS, was found to depend on the nature of the existing bonds before the illness and how the individual has contributed to the relationship. A male ARV user noted:

“If you don’t have a partner you are in trouble. The partner can take care of you when you are sick. The parents may say you only know them when you are sick, you used to go around with other ladies when you were fit. They deny you and offer you negative support.”

A female home based care volunteer observed that:

“Some of the patients are suffering. There is one man who is suffering because his wife does not want to care for him. She does not cook for him and does not give him his medicines. We sometimes try to bring him food but when she sees us, she chases us away. The man is so thin.”

Within the same family, some members may be more supportive than others, as a female ARV user explained:
“I get support from my sister and my children. My nieces, they are always laughing at me and telling people that I have the virus. They would not even give me my medications when I am too sick.”

Most ARV users said they would not disclose their HIV status and the fact that they are on treatment to anyone if they believed it would result in stigmatization and a lack of support. Unresolved family conflicts may also result in lack of support. This was captured in the story of an ARV user, who said:

“My discrimination did not start with my HIV status but emanated from family conflict. I ended up moving out of the family home with my children. I continued to meet obligation to the family but when I got ill and was hospitalized, they never visited me. Currently my parents have passed away. However, if there is illness or death of one of our relatives I do assist.”

c) Workplace

Many of the respondents interviewed, especially those who worked as shop assistants, farm workers cited non-release by employers as a barrier to adherence to treatment. Many of these workers said they could not even freely discuss the issue of their HIV status and treatment at work, for fear of being victimized by their employers. One ARV user said:
“I was once illtreated in my workplace and forced to transfer to a place about 400 kilometres away but I am supposed to see the doctor. I resigned from the work because I preferred to stay close to my treatment site.”

A female ARV user, who works as a shop assistant said:

“I resorted to asking my relatives to pick up my medications because my employer refuses to release me to go and pick up my medications.”

For these people, difficulties with transportation to attend clinics for treatment monitoring and medicine refills were major issues of concern.

One of the health workers explained:

“For most employees, transport to health facilities poses a problem. Some employers do not release their workers.”

Most of the ARV users interviewed believed that more should be done by the Government to protect PLWHIV in the workplace, as this would help improve adherence.

4.6.1.4 Logistics and costs

The patients do not pay for ARVs offered within the public health facilities. Logistics and costs were therefore viewed in terms of the availability of transport, transport related costs, lost wages, money spent on snacks and food while attending appointments, and other treatment related costs, as perceived by the ARV users.
In the qualitative survey, the health workers reported lack of transport – either no means of transport or no money to pay the fare as the reason most frequently cited by patients for failing to attend the clinic for treatment review or medicine refill. Many ARV users, especially those who were not employed, said that lack of money to pay for transport was a problem. Some ARV users complained that the treatment centre was too far away and not always easy to access. An ARV user who had to travel far to get a medicine refill said:

“I once missed my appointment for refill because there were no vehicles coming here due to a matatu strike. I was at the bus stop from early morning and by noon I went back home. Fortunately I still had some medications.”

4.6.1.5 Misconceptions about ARV drugs
There were some concerns among ARV users about the language used to communicate the results of laboratory tests to patients. As one ARV user said:

“One of the patients stopped the medicines because he was told that his viral load was undetectable, so he stopped taking his pills because he thought he was cured.”

4.6.1.6 Alcohol and substance abuse
Alcohol abuse was cited as one of the reasons why some patients are not adhering to medication. One of the respondents said:
“Some of the patients who take alcohol end up forgetting to take their tablets or omitting treatment.”

Another respondent said:

“Those who take alcohol sometimes lose their drugs in the bars when they are drunk.”

4.6.2 Facilitators of adherence to ART
In the efforts to identify facilitation to adherence six main themes emerged. These are presented below, not in order of priority.

4.6.2.1 Acceptance of HIV status and disclosure
Most respondents (ARV users, community and health care workers) agreed that individual acceptance of HIV status was key to the necessary behavioural change that is required for good health outcomes.

One of the ARV users said:

“Since the beginning, I told myself that this disease is just a disease like any other disease. You should accept yourself.”

Similarly, another ARV user said:
“As long as one has accepted his/her situation and is committed to treatment, there will be no problems.”

4.6.2.2 Belief in the efficacy of ARVs in treatment/pre-treatment health state
The fear of relapse or perceived vulnerability to negative outcomes from suboptimal adherence was considered to be a major motivator of adherence. Most of the respondents stated that, despite being often preoccupied with their own health concerns and fears, the availability of ARVs had given them a “new lease of life. Some of the respondents stated that individuals were motivated to begin treatment if they experienced a decline in their health status, believed that therapy would prolong life, and believed that they could cope with the treatment regimen and its potential side effects. One of the respondents, whose health had improved as a result of taking the ARVs stated that:

“If you had seen me a few months ago I could hardly get out of bed. I was like this (showing the smallest finger). Now here I am. You cannot even believe it. If you have been there, you will take them (ARVs).”

Another male ARV user from Kibera also stated that “di ne ong yien gi di koro asetho chon” which meant: “were it not for ARVs I would be long dead.”

4.6.2.3 The need to care for others
The desire to stay alive can be greatly reinforced by the recognition that your loved ones might not cope in your absence. Women were found to be always concerned about their children and aged parents. The desire to continue to be around for them for
their sake was found to be a critical motivator for most women. These sentiments were shared by other female respondents:

“We give birth to children, and we don’t want to orphan our children... I don’t want my children to be raised by a stepmother. Fathers are not good at raising children.”

“As women, we feel pity for our aging parents, especially if the other children are irresponsible. You wonder who is going to take care of the parents if you were to die first.”

“I am sure my children need me. I am afraid of dying and my baby has to suffer without me. My children are the best things that ever happened in my life. And I am wondering how they would feel if they had to lose me.”

4.6.2.4 Social support as determinant of adherence
Social support is based on the kind of relationships and interactions that provide individuals with assistance or feelings of attachment. Generally, most respondents argued that the availability of social support was critical for good adherence to ART. Children were reported to be among the main providers of social support, with older (primary or secondary school age) children taking a leading role in reminding the parent (often their mother) of pill times. For those in stable relationships, the availability of social support from the partner was determined by whether that partner had tested and, if so, whether they had accepted their status. One of the respondents said:
“I once went to my mother and told her that I am taking lifelong treatment and she accepted me. My husband also accepted me. He is the one who wakes me up to come for treatment.”

Another said:

“My husband is HIV negative but he always reminds me to take my ARVs. My children also remind me.”

4.6.2.5 Effective adherence counseling

Adherence counseling is aimed at promoting adherence to ARVs and preventing further transmission of HIV. The respondents stated that they had received counseling before the initiation of therapy. The issues covered included: HIV and AIDS; mode of transmission; prevention methods; how ARVs work; the importance of adherence; side-effects and how to minimize them; interactions between ARVs and other medicines (including traditional medicines) and alcohol. The effectiveness of the counseling process was highlighted by some respondents who stated that, even though they do experience side effects, they continue to take the medicines because they were warned about possible side effects and informed that they would go away. Some also said they were given written information about this to take home. One of the female ARV users said:
“I learnt that I should not skip the medicines and I should adhere to the stipulated time. At one stage I skipped them and took them after the stipulated time. I told my nurse and I was assisted.”

Some of the participants pointed out that there was also a need for continued counseling. One female ARV user said:

“Even though initially we are given a lot of information, counseling is not adequate because it is only done once. Follow up at home should be done to find out if one is really taking the medicines.”

Similarly, a health care provider pointed out that:

“Patients are given information during the initiation of treatment but it is necessary to continue reminding them...”
4.7 THE QUALITY OF CARE PROVIDED TO THE PEOPLE LIVING WITH HIV AND AIDS BY THE HEALTH CARE WORKERS

4.7.1 Tasks and training of the health care workers

The health care workers were asked to state whether they had received any training on care and management of people living with HIV and AIDS per se and the results indicated that majority of them (85%) had received some training on care and management. They were further asked to state the contents of the training that they had received with a possibility of giving multiple responses in cases where the training contents. The Table 4.5 below shows some of the areas covered by the training. Multiple responses was allowed for the respondents.

Table 4.5: The specific areas covered in the training of health workers (n=40)

<table>
<thead>
<tr>
<th>Specific area of training</th>
<th>Proportion of health workers trained (%)</th>
<th>Proportion of health workers NOT trained on the area (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult and Paederiatic ARVS</td>
<td>28(70)*</td>
<td>12(30)</td>
</tr>
<tr>
<td>ARVS adherence counseling</td>
<td>36(90)</td>
<td>4(10)</td>
</tr>
<tr>
<td>Prevention of mother to child transmissions (PMTCT)</td>
<td>24(60)</td>
<td>16(40)</td>
</tr>
<tr>
<td>STI managements</td>
<td>24(60)</td>
<td>16(40)</td>
</tr>
<tr>
<td>Nutrition and HIV/AIDS</td>
<td>16(40)</td>
<td>24(60)</td>
</tr>
<tr>
<td>Diagnostic testing and counseling</td>
<td>28(70)</td>
<td>12(30)</td>
</tr>
<tr>
<td>HIV/TB Co infection</td>
<td>30(75)</td>
<td>10(25)</td>
</tr>
<tr>
<td>Voluntary Counseling and Testing (VCT)</td>
<td>32(80)</td>
<td>8(20)</td>
</tr>
<tr>
<td>Management of Opportunistic infections</td>
<td>24(60)</td>
<td>16(40)</td>
</tr>
</tbody>
</table>

*Numerals in parenthesis refer to proportions expressed in percentages

The health care workers were then asked if in their opinion they thought the training was sufficient and the results indicated that more than half (60%) thought it was...
sufficient while about 40% still believed that the training was not sufficient enough for them to handle the patients well.

4.7.2 Drug availability and treatment procedures by the health workers

All the health care workers admitted that they were using the national antiretroviral therapy guidelines for management of their patients. When they were asked if the drugs were always available about 70% were on the affirmative with another 30% admitting missing some drugs although rarely. The health care workers were then asked for some of the reasons for the lack of drugs at the clinic and majority of them (90%) said it was due to the bureaucracy in the procurement or obtaining the drugs. They were then asked to state what they did in cases when there were no drugs the Figure 4.19 below summarizes their responses.

![Figure 4.19: Actions taken by the health workers when drugs are not available in stock at the facility](image)

Figure 4.19: Actions taken by the health workers when drugs are not available in stock at the facility

The health workers were then asked if they had a CD4 machine at the facility and about 60% said they had a machine with 40% not having a CD4 machine. In terms of how the specimen was handled most of the facilities without a CD4 machine picked
specimen from the patients and took elsewhere for measuring and asked the patients
to come back later for the results of the CD4 counts.

4.7.3 Adherence issues from the perspective of the health providers
The health providers were asked to state whether they thought their patients kept
appointments and the results indicated that 30% of the health workers saying that the
patients do not keep appointments. However, 70% stated that their patients kept
appointments. They were later asked to state what proportions of the patients they
thought were strictly adhering to the treatment. The results indicated that most (60%)
health workers thought that between 50 to 75% of the patients adhered to treatment
and none of the health workers thought all patients adhere to treatment. The Figure
4.20 below shows the results on the estimation by health workers of proportion of
patients who sufficiently adhered to treatment.

![Figure 4.20: Estimation by health workers of proportion of patients who sufficiently
adhered to treatment.](image-url)
4.7.4 Challenges faced by the health workers in supporting the patients to adhere

The health care workers were then asked to state some of the challenges they faced in an attempt of having the patients. The challenges stated by the health workers were varied. They included

i. Majority of patients suffer from side effects and other drug toxicities which make it difficult for them to adhere to treatment

ii. Some of the patients use other drugs concurrently for instance the patients taking anti-TB drugs and contrimoxazole (CTX) may find it difficult to adhere to the ARVs

iii. Some of the patients especially those who are using second line drugs with a higher pill burden may have problems adhering to treatment

iv. Some patients may lie to the health workers that they have taken drugs when indeed they have discarded them

v. Some of the patients lack money for transport to the facility hence they may not keep appointments strictly

vi. Some of the patients are poor and may not meet the nutritional requirements needed for some of the drugs and hence may not adhere

vii. There are cases of some patients transferring to other facilities without notice probably due to the fear of stigmatization hence making it difficult to follow the progress of such patients

viii. There are some patients who are abusers and addicts of alcohol and cigarette smoking hence making it difficult to adhere to ARV regimen
4.7.5 Working conditions and support given to health care staff

The health care staff were asked for some of the difficulties they faced in their line of duty. The major issues raised included excess workload, stress and burnout as a result of them being few in numbers.

They were then asked if they had any fears now that they were working in the HIV clinics. Majority (90%) of the workers admitted to having a lot of fears in their line of duty. Some of the fears raised by the health workers includes, the risk of infection through needle pricks during treatment or when taking samples as well as handling contaminated materials. Other fears were of contacting air borne infections especially for the patients with Pulmonary Tuberculosis (PTB) who may cough while undergoing treatment.

4.7.6 Suggestions by health workers for improving the quality of care given to the patients

The health care workers had the following suggestions to help improve the quality of care given to the PLWHA

- More frequent support supervision atleast every 6 months
- Avail post exposure prophylaxis (PEP) to the health care workers all the time
- Increase the number of staff to reduce burn out and excess workload
- Further and frequent training of the health care staff on new service delivery methods
CHAPTER FIVE : DISCUSSION

5.0 Introduction
This chapter describes the discussion of the results of this and relates it to the literature from related studies. It elaborates the similarities and differences between the results of this study and those done by others on the same topic.

5.1 SOCIO-DEMOGRAPHIC CHARACTERISTICS OF THE RESPONDENTS

5.1.1 Age of the Respondents
The results indicated that majority of the respondents were aged between 30-35 years of age with the lowest being from the age group 18-25 years. The results of this study concur with the findings from KAIS (2007) which state that the age group that is mostly affected by HIV and AIDS is 30-40 years. The results indicated that older people are more likely to adhere to treatment a finding similar to the findings by Jones et al., 1999 who stated that adherence increases with age.

5.1.2 Sex of the respondents
The majority of the respondents were females (62.2%) with the males only comprising 37.8%. The results indicated that there were more females affected by the HIV and AIDS compared to the males. These results concur with those by KAIS (2007) which state that a higher proportion of women age 15-64 (8.7 percent) than men (5.6 percent) are infected with HIV. This pattern is similar to what was observed in the Kenya Demographic and Health Survey of 2003.
5.1.3 Education level of the Respondents
The results of the study indicated that majority (50%) of the respondents had attained at least college or university level of education. The results indicated that women age 15-64 with higher educational levels have significantly lower HIV prevalence than those with less education similar to those of KAIS (2007). The results also indicated that there was a significant correlation between the level of education and the utilization and adherence to ART services with those who have higher levels of education being more likely to use the service. The results concur with those found by Catz et al., (1999) who also stated that a lower level of education impacts negatively on the patient’s ability to adhere to treatment.

5.1.4 Marital status
The results of this indicated that those currently married or formerly married are at the highest risk of infection. This may be because condom use in the relationship is less likely and in case one of the partners is unfaithful then there is a likelihood that HIV may be transmitted more easily. On the other hand those who are not marriage are more likely to use protection because they consider every action a high risk one. Another hypothesis is that the deceased partners of women respondents are likely to have died from HIV-related illness after years of infection, since HIV is the leading adult cause of death among Kenyans age 15-49. These women were potentially exposed to HIV for several years before their partners died.
5.2 KNOWLEDGE, ATTITUDES, BELIEFS AND PRACTICES RELATING TO ANTI-RETROVIRAL THERAPY

5.2.1 Knowledge of ARVs
The results indicated that 48% of the respondents had adequate knowledge of ARVs while 52% did not have adequate knowledge of ARVs. There was a correlation between the knowledge level and the level of adherence with those with higher knowledge tending to adhere to treatment more than those with lower level of knowledge. The results of this study concurred with those which stated that a good level of understanding about HIV by the patient, a belief that ART is effective and prolongs life, and recognition that poor adherence may result in viral resistance and treatment failure (Wenger et al., 1999) all impact favourably upon a patient’s ability to adhere. Conversely, a lack of interest in becoming knowledgeable about HIV and a belief that ART may in fact cause harm adversely affect adherence.

5.2.2 Sharing the results of the HIV test
Majority of the respondents did not share the results of their HIV test for fear of discrimination and stigmatization. This is probably due to fear of being discriminated by the friends and relatives if found to be HIV positive.

5.2.3 Experience of the Side effects of ARVS
The results showed that majority of the respondents (87%) had experienced some side effects with only 13% stating they had not experienced any side effects. These results concur with those found by Burgos et al.,(1998), who also found out that the existence of side effects is likely to influence adherence levels.
5.2.4 Use of other medicines in combination with the ARVs
The results indicated that most of the (70%) were not using other drugs. It was however noted that a small proportion of 30% were using others drugs which could affect the outcome of the medication. The use of other drugs was found to interfere with adherence with most of the patients using failing to adhere. However none of the other drugs they were using could not have any side effects since they were mainly pain killers to deal with some opportunistic infections.

5.2.5 Disclosure of taking ARVs
The results indicated that for the majority of the respondents, the spouses (35%) were aware that they were taking ARVs. The results indicated that those who had disclosed to the relatives and friends that they were taking ARVs were more likely to adhere to treatment because they had support from them. However those who had kept the fact that they were taking ARVs secret were more likely to default because the time for taking the drugs would come when they are with other people and this would make them default as they had to hide.

The results also concur with those by Williams and Friedland (1997), who said that living alone and a lack of support have been associated with an increase in sub-optimal adherence and social isolation is predictive of sub-optimal adherence. Not living alone, having a partner, social or family support, peer interaction, and better physical interactions and relationships are characteristics of patients who achieve optimal adherence (Motashari et al., 1998).
5.2.6 Ever Missed any medication since beginning treatment
The results indicated that nearly half 196(49%) of the respondents had missed some medication with just over half of the respondents had not missed any of the medication. There were a variety of reasons that made the patients to miss medication.

This results concur earlier results that postulate that the likelihood of a patient 's adherence to a given regimen declines with polypharmacy, the frequency of dosing, the frequency and severity of side -effects, and the complexity of the regimen (Williams and Friedland, 1997).

5.2.7 Whether the patients had ever changed the regimen
The results indicated that about 45% had at least changed treatment regimen, with about 55% not having changed their treatment regimen. They were further asked to state some of the reasons that may have made them to change the treatment regimen. The changing of the regimen usually is done by the patients on the recommendation of the physician if the patient is having adverse reactions to some drugs.
5.3  Factors that promote or constrain adherence to ART

5.3.1  Duration taken to the health facility
The participants were asked to estimate in time how much time they took by public means to travel from home to the health facility, the results indicated that majority (35%) took between 30min to 1 hour to get to the facility. The patients who take along duration to travel to the health facility are less likely to adhere especially if they run out of drugs completely and have not gone for a refill. It was also noted that some of the patients prefer to go for drugs at places far away from where they stay probably due to the fear of being stigmatized and discriminated.

5.3.2  Ways of remembering to take the pills
The patients who were taking the pills were asked to state some of the ways that they had used for remembering to take pills. The most common method used to remember when to take the pills was the cell phone or clock (42%). The others used friends (7%), Relatives (12%), Meal times (30%) and self conscious (8%). The use of cell phones or clocks as reminders are quite good to enable patients adheres and actually take the drugs at the right time intervals.

5.4  HIV transmission high risk behaviours among patients on ART

5.4.1  Having sexual intercourse in the past six months
The respondents were asked whether they had engaged in sexual intercourse in the last six months. Most of them admitted to having sexual intercourse within the period. This is because once the patients begin ART, their immune systems and health status
may improve, and many are able to engage in sexual activity. The results of this study concur with those by Valasco-Hernandez et al.,(2002) who conclude that ART significantly enhances quality of life and personal sense of well being, enabling many individuals to resume sexual activity- which may involve risky behaviour. While this can be an important benefit of the therapy it could also increase opportunities for HIV transmission.

5.4.2 Disease stage at the start of ART and sexual activity
Patients who had initiated ART with advanced HIV disease (CD4 cell counts < 100 cells/mm³) were significantly less likely to report sexual activity in the past six months compared to respondents who had initiated ART with higher CD4 cell counts (P ≤ 0.037). This is because most of them were sick and did not have the energy or were still having some opportunistic infections that were evident and could discourage the potential partners.

5.4.3 The type of sexual partner with whom they had sex
Ninety-three (93%) percent of respondents who reported being sexually active in the past six months reported having sexual intercourse with a regular partner. This is because those who had been having sex with the regular partners were doing so with their spouses or boy/girlfriends with whom were easy to find and make sexual advances. All the respondents who reported sex with a casual partner or a sex worker were male. This is mostly because the of gender norms which give the males more “freedom” to have multiple sexual partners.
5.4.4 Knowledge of the HIV status of the partners at the time of sexual intercourse

 Respondents were asked whether or not they knew the HIV status of their regular partner. Overall 83 percent of respondents who reported sex with a regular partner reported knowing their partner’s HIV status. This was because due to lack of knowledge that even though they were already infected they would still get re-infection and that would complicate the rate at which they recover from the episodes of opportunistic infections.

5.4.5 Disclosure of own HIV status to regular partner

74 percent of respondents reported having disclosed their HIV status to their regular partner, and 98 percent of these individuals were married. However, even though a significant number of respondents believed that disclosing to relatives and friends had the potential to improve adherence, some of them also perceived that disclosure carried a number of risks such as: emotional injury, loss of intimate relationships and job loss. Other studies have also found that disclosure is a complex process with varying consequences, such as greater intimacy or rejection, feeling of relief or remorse and enhanced status or spoiled image (Ormazu, 2000; Klitzman et al., 2004; Zea et al., 2005).

5.4.6 Use of condom during the last sexual intercourse

The respondents who had engaged in sexual intercourse were then asked whether they had used a condom in the last sexual encounter. The results indicated that only 27% had used a condom in the last sexual encounter. A huge proportion of over 72% however did not use a condom during the last encounter. These results also concur
with those of a study by JHA (2001) who stated that the rates of condom use decline in PLWHA after some time.

5.4.7 Condom use with a regular partner
Respondents with lower levels of education reported significantly lower condom use compared to those with higher levels of education. Condom use was more common with an HIV-negative partner.

Ninety-six percent of respondents with an HIV-negative partner reported using a condom at last intercourse compared to 83 percent with a HIV positive partner and 87% with a partner of unknown HIV status.

5.4.8 Respondents intending to get married after starting ARVs
The 171 respondents who were not married at the time of the study were asked whether they were intending to get married now that they knew that they had been infected by HIV. The results indicated that (89) 52% were intending to get married while (82)48% did not see any need for getting married. Of the respondents who wanted to get married, 58% were females while 42% were males. The results also indicated that most (91%) of the respondents who wanted to get married were below the age of 35 years while only 9% who wanted to get married after knowing their status were aged above 35years. On education level, majority (91%) of those who wanted to get married had at least secondary education with only 9% having no formal education or primary level of education.
5.4.9 Intending to have children
The respondents were then asked whether they were intending to get children now that they were HIV positive. The aim was to find out if they still would have wished to have any more children especially after knowing that they were suffering from a terminal illness. The results indicated that 40% of them wanted to have children while 60% did not want to have children. This means that the people living with HIV and AIDS still wanted to have children since they looked health and believed that they will live long enough to take care of the children.

5.5 FOCUSED GROUP DISCUSSIONS RESULTS
5.5.1 Constraints to adherence to ART
In the discussions on determinants of adherence, the study identified six interrelated themes. These are presented below, without any order of priority.

5.5.2 Gender and non-acceptance of HIV status
Gender was identified as being strongly associated with acceptance of HIV status. Respondents stated that women talk about HIV and test early, and so are more likely to accept their status than men. Men were said to avoid testing for HIV. But when their partners test first, they often blame them for bringing the virus. As a result, men can become angry and violent and tell the partner not to bring the medication into the (‘his’) home. Women were more likely to accept their HIV status than men and they generally have better health seeking behaviour than men. The better health seeking behaviour of women to be due to their desire to stay alive in order to care for their children and other loved ones, despite being blamed by men for the disease.
5.5.3 Non-disclosure

Most respondents stated that failure to tell someone (e.g. a friend or family member) are due to reasons such as: fear of being discriminated against, stigma, job loss or abandonment. It was not uncommon to hear of people who were rejected by their partners because they had revealed their HIV status. Men, on the other hand, complained that women do not disclose their status in order to keep them in the relationship.

If one partner is on ART, they may resort to pill hiding, occasional skipping of medications and failing to keep clinic appointments for refills or review, so their partner does not find out that they are on ART.

5.6 Facilitators of adherence to ART

5.6.1 Acceptance of HIV status and disclosure

Most respondents (ARV users, community and health care workers) agreed that individual acceptance of HIV status was key to the necessary behavioural change that is required for good health outcomes.

5.6.2 Belief in the efficacy of ARVs in treatment/pre-treatment health state

The fear of relapse or perceived vulnerability to negative outcomes from suboptimal adherence was considered to be a major motivator of adherence. Most of the respondents stated that, despite being often preoccupied with their own health concerns and fears, the availability of ARVs had given them a “new lease of life. Some of the respondents stated that individuals were motivated to begin treatment if they experienced a decline in their health status, believed that therapy would prolong
life, and believed that they could cope with the treatment regimen and its potential side effects.

5.2.3 Social support
Social support is based on the kind of relationships and interactions that provide individuals with assistance or feelings of attachment. Generally, most respondents agreed that the availability of social support was critical for good adherence to ART. Children were reported to be among the main providers of social support, with older (primary or secondary school age) children taking a leading role in reminding the parent (often their mother) of pill times. For those in stable relationships, the availability of social support from the partner was determined by whether that partner had tested and, if so, whether they had accepted their status.

5.2.4 Effective adherence counseling
Adherence counseling is aimed at promoting adherence to ARVs and preventing further transmission of HIV. The respondents stated that they had received counseling before the initiation of therapy. The issues covered included: HIV and AIDS; mode of transmission; prevention methods; how ARVs work; the importance of adherence; side effects and how to minimize them; interactions between ARVs and other medicines (including traditional medicines) and alcohol. The effectiveness of the counseling process was highlighted by some respondents who stated that, even though they do experience side effects, they continue to take the medicines because they were warned about possible side effects and informed that they would go away.
CHAPTER SIX: SUMMARY OF CONCLUSIONS, RECOMMENDATIONS AND SUGGESTIONS FOR FURTHER RESEARCH

6.0 Overview of summary, conclusions and recommendations
This chapter sums up the key findings from this research; outlines the implications of study findings; conclusions based on the research findings; recommendations and suggestions for further research.

6.1 Summary of findings
The study set out to establish the determinants of adherence to ART and the high risk behavior among patients on ART. The study demonstrates that the specific objectives and the research questions were fully met. The findings indicated that 48% of the respondents had adequate knowledge of ARVs while 52% did not have adequate knowledge of ARVs. Having accurate knowledge of HIV and AIDS as well as ARVs was found to have an influence on the level of adherence.

The study findings indicated the composite level of adherence to be 85% in Nairobi province, Kenya and is less than the optimum adherence level necessary for the suppression of viral multiplication and improvement of CD4 cell count which are necessary to reduce morbidity and mortality due to HIV and AIDS.

The results further showed that majority of the respondents (87%) had experienced some side effects with only 13% stating they had not experienced any side effects. The critical barriers to adherence identified were: forgetfulness, lack of transport fare to the health facility, non acceptance of HIV status, fear of discrimination and stigma, alcohol abuse, and non supportive home and work environments. The facilitators of
adherence on the other hand were found to include self-efficacy, social support, an effective adherence counseling programme, perceived benefits of the medication, and a desire to stay alive for the sake of others.

Majority of the respondents (76%) indicated that they were still sexually active with only 27% stating that they had used a condom in the last sexual encounter. This meant that there was a risk of transmitting HIV to the partners or even getting new stains of the HIV virus which would lead to drug resistance and eventually lead to burden in the health care system.

6.2 Conclusions
i) Only 48% of the patients living with HIV and AIDS and are currently on treatment have accurate knowledge of what HIV and AIDS and ARVs drugs are.

ii) The level of adherence to ART in Nairobi province was found to be 85% which is sub-optimal though similar to what has been found in other developing countries (Weiser, 2003, Omes, 2004)

iii) Forgetfulness, lack of transport fare to the health facility, non acceptance of HIV status, fear of discrimination and stigma, alcohol abuse, and non supportive home and work environments were critical barriers to adherence.

iv) Proper social support, an effective adherence counseling programme, perceived benefits of the medication, and a desire to stay alive for the sake of others were facilitators of adherence
v) Majority (76%) of the patients are sexually active and engaging in risky sexual behaviours with only 27% admitting to having used a condom in the last sexual exposure

6.3 Recommendations
In order to ensure that all patients achieve optimum adherence level and reduce high risk sexual behaviour, this study recommends to the Ministry of Medical Services, Ministry of Public health and sanitation as well as any other interested stakeholders such as NACC and NASCOP that:

i. The Ministries of Public Health and Sanitation, Medical Services and National AIDS Control Council (NACC) should ensure that more information was given to patients on HIV and AIDS as well as ARVS especially during adherence counseling by the health providers.

ii. The Ministry of Medical Services should ensure more intensified measurements of adherence was done including the development of practical guidelines for: continuous adherence counselling; bringing treatment closer to home; adoption of a family care model approach to ART and use of practical reminders.

iii. The Ministry of Medical Services enforce adoption of a uniform adherence monitoring system at all facilities in Nairobi with simple and practical tools such as pill count register and the visual line one-month recall. These measures need to be validated and standardized. Data generated should be reviewed periodically in order to monitor the rate and trend of adherence to ART.
iv. The National AIDS Control Council (NACC) should ensure sustained community mobilization aimed at mitigating stigma and discrimination in an effort to create an enabling environment in which people can disclose and take their ARVs without fear of discovery and or stigmatization.

v. The NACC and NASCOP should enforce the adoption and promotion of the prevention among the positives by targeting the people living with HIV and messages enable them adopts safer sexual practices.

6.4 Suggestions for further research
Acceptance of HIV status, disclosure and gender were found to be the main emerging themes in the qualitative data. Further studies are needed to explore these variables in greater depth.

Many opportunities for future research are evident in the study of antiretroviral adherence behavior among older HIV-infected patients. In particular, a great need exists to investigate the impact of Opportunistic infections and use of concurrent medications on adherence behavior of older patients with HIV. Psychological research to identify better methods of predicting medication adherence may serve to inform medical decision making regarding optimal treatments.

Furthermore, the association of inadequate access to medications or interruption of an individual patient’s pattern as a result of the incidental missing of medications should be an area of consideration. Effective intervention strategies that affect adherence also should be included in topics for future research agenda. Finally, the role of alternative
medicines and their effect on adherence should be further investigated among older patients using antiretroviral medication especially in the rural areas.

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APPENDIX I: SEMI-STRUCTURED INTERVIEW WITH ARV USERS

(Instruction to the interviewer: Read this consent form aloud and clearly to the respondent)

Good morning/ Good afternoon. My name is John Paul Oyore. I am a Doctor of Philosophy (PhD) student at Kenyatta University, Nairobi. I am here to carry out a study on the levels of adherence, its determinants and any high risk behaviour among HIV patients. The information you give is important and therefore kindly be sincere in your responses.

Some of these questions will be about your personal life. I am aware that some of these questions are sensitive, but the information you give me will be kept strictly confidential and at no time will you be required to identify yourself by name.

Your participation in this study is voluntary. You can refuse to answer all or some of the questions but I will appreciate your help in answering all the questions. It is important to note that your participation will not affect your ability to use health facilities or any other services. I am hoping that you will participate since your participation and views are highly valued and important.

Declaration
I have been informed about this study and understand its purpose and objectives. I understand the details, have been informed about the requirements and hereby agree to participate in the study

Signature of Respondent........................................Date..........................
Signature of interviewer........................................Date .........................
SEMI-STRUCTURED INTERVIEW WITH ARV USERS

<table>
<thead>
<tr>
<th>Name of the interviewer</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview number:</td>
<td></td>
</tr>
<tr>
<td>Name of health facility</td>
<td></td>
</tr>
<tr>
<td>Date of interview</td>
<td></td>
</tr>
</tbody>
</table>

INTRODUCTION

INTRODUCTION OF THE STUDY, CONSENT REQUESTED WITH OPTION NOT TO PARTICIPATE. STATEMENT OF CONFIDENTIALITY.

1. SOCIO-DEMOGRAPHIC INFORMATION ON INFORMANTS

a) Sex

<table>
<thead>
<tr>
<th>Male</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td></td>
</tr>
</tbody>
</table>

b) Age (Years)

| 18 to 25 years |  |
| 25 to 30       |  |
| 30 to 35       |  |
| 35 to 40       |  |
| Over 40 years  |  |

c) Highest Educational level

| Illiterate    |  |
| Primary       |  |
| Secondary     |  |
College/university [ ]

d) Who do you live with?

Spouse [ ]

Children, [ ]

Parents [ ]

Others – Specify [ ]

e) What do you do for a living (occupation)

Employed [ ]

Not employed [ ]

f) What is your average income per month (ksh)

Below 5000 [ ]

5000 to 10000 [ ]

10000 to 15000 [ ]

More than 15000 [ ]

g) Distance from facility (in time)

Less than 1 hour [ ]

1 to 2 hours [ ]

More than 2 hours [ ]

2. MEDICAL HISTORY OF PATIENT

a) When were you first diagnosed with HIV? Or state Month and year ---------------

Less than 6 months ago [ ]

6 months to 12 months ago [ ]

12 months to 24 months ago [ ]
More than 24 months ago [ ]

b) What made you decide to go for testing?

- Was sick/undergoing treatment [ ]
- Partner positive [ ]
- Was expectant (PMTCT) [ ]
- Others – specify [ ]

c) When did you start treatment for HIV (ARVs)? Or state Month and year -------

- Less than 6 months ago [ ]
- 6 months to 12 months ago [ ]
- 12 months to 24 months ago [ ]
- More than 24 months ago [ ]

d) How do you feel about your health since you started treatment?

- Better [ ]
- Same [ ]
- Worse [ ]

3. PATIENT KNOWLEDGE ABOUT HIV/AIDS

Can you tell me what you know about HIV/AIDS? (Allow patient to say what they want, then probe on the following: cause of HIV infection, cause of AIDS, prevention, life-long infection).

……………………………………………………………………………………………………………………………………

……………………………………………………………………………………………………………………………………

……………………………………………………………………………………………………………………………………
Apart from this, is there anything else you may have heard from your community that explains AIDS in a different way?

4. PATIENT KNOWLEDGE ABOUT ARVS

What are ARVs

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

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

What do ARVs do

  Treat HIV [ ]

  Suppress viral replication [ ]

  Prolong life [ ]

Do they have side effects?

  Yes [ ]

  No [ ]

What are some of the side effects

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

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

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

5. ASSESSMENT OF ADHERENCE AND NON-ADHERENCE

We are trying to find out how patients manage to take their medicines – for some people it’s not a problem, but we also know that others don’t always
find it easy. Please feel free to be open about the problems you face with this. Everything you say here will remain confidential, and will not be shared with anyone at the clinic.

a) Do you have your medicines with you? May I see them? Please can you tell me When do you take each of the medicines?

…………………………………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………
………………

b) Are there any other medications you are taking apart from the ones given at this clinic

Yes [ ]

No [ ]

If yes from where did you get the medicine

Traditional medicines [ ]

Herbs [ ]

Medicines from other hospitals [ ]

From the shops/chemist, etc.) [ ]

c) Over the last two days, when did you take your pills? (Not including today – starting from last night and back.)

Please shade on the on the chart below to show how many of your ARV pills you think you managed to take in the last one month
Can I see you medicine please? Complete the names and number of pills

<table>
<thead>
<tr>
<th>Drug name</th>
<th>Pills per day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drug A</td>
<td>Pills per day</td>
</tr>
<tr>
<td>Drug B</td>
<td>Pills per day</td>
</tr>
<tr>
<td>Drug C</td>
<td>Pills per day</td>
</tr>
<tr>
<td>Drug D</td>
<td>Pills per day</td>
</tr>
</tbody>
</table>

Now try to remember the last two days, when did you take each of the medicine

**Yesterday**

<table>
<thead>
<tr>
<th>a.m</th>
<th>p.m</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please mark when you took each drug

| Drug A | |
|--------||
| Drug B | |
| Drug C | |
| Drug D | |

**Day before yesterday**

<table>
<thead>
<tr>
<th>a.m</th>
<th>p.m</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please mark when you took each drug

<p>| |</p>
<table>
<thead>
<tr>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Drug A</td>
</tr>
<tr>
<td>Drug B</td>
</tr>
<tr>
<td>Drug C</td>
</tr>
<tr>
<td>Drug D</td>
</tr>
</tbody>
</table>

Number of boxes---------------------
PILL COUNT - TO BE DONE AT THE PHARMACY

Please indicate for each ARV medicine

1. How many pills the patient should have taken in the last visit and
2. How many s/he missed (how many extra pills were returned)

<table>
<thead>
<tr>
<th>Drug name</th>
<th>Example</th>
<th>Drug A</th>
<th>Drug B</th>
<th>Drug C</th>
<th>Drug D</th>
</tr>
</thead>
<tbody>
<tr>
<td>Previous date issued</td>
<td>6 Jan 07</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Qty taken home (Total)</td>
<td>67</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Qty returned</td>
<td>15</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date returned</td>
<td>3 Feb 07</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Days since last issue</td>
<td>28</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regimen</td>
<td>2 bid</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total supposed to take</td>
<td>56</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Should have returned</td>
<td>67-56=11</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pill missed</td>
<td>15-11=4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Percent adherence</td>
<td>(56-4)/56 *100</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adherence level</td>
<td>92%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

d) Did you perhaps miss any?
   Yes [  ]
   No [  ]

Details if yes.)

..............................................................................................................................................
..............................................................................................................................................
e) If you sometimes miss a dose, please can you tell me what causes this to happen? Which of the following reasons has ever made you skip your medication?

(More than one answer allowed) Tick as appropriate

<table>
<thead>
<tr>
<th>Reasons</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Felt better</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinic not accessible</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cost of ARVs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of food</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pill burden</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of care and support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospitalized</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depressed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did not understand instructions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shared pills</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Distance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alcohol use</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Didn’t have pills</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having to hide medication from those around you</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

f) On the other hand, what is it that *helps* you to take your pills regularly and on time?

- Friends [ ]
- Relatives [ ]
- Cell-phone, clock [ ]
- Other – specify [ ]

g) Have you disclosed your status to any one?

- Yes [ ]
- No [ ]

If so, who?

- Friends [ ]
h) Have you had your treatment changed at any moment since you were started on ARVs?

Yes [ ]
No [ ]

If yes, why?

Treatment failure [ ]
Side–effects [ ]
Drug not available [ ]
Other – specify [ ]

Have you ever missed an appointment at your health centre?

Yes [ ]
No [ ]

Reasons for missing an appointment

…………………………………………………………………………………………

…………………………………………………………………………………………

j) What do you think happens in your body if you skip your ARV medicines?
k) Have you ever thought about stopping HIV/AIDS medicines (ARVs)?

Yes [ ]

No [ ]

If yes why

…………………………………………………………………………………………

…………………………………………………………………………………………


6. PERCEPTION ABOUT HIV/AIDS, ARVS AND STIGMA

Have you ever had any experience of being treated differently because of your HIV status? (in your family, at work, at the church etc). If Yes, give details

…………………………………………………………………………………………

…………………………………………………………………………………………


7. COST CONSIDERATIONS

a) How much do you have to pay to cover your travel expenses when you visit the clinic? (Ksh)

Kshs ---------------

b) What is the cost of registering at the clinic in Ksh (if any)?

None [ ]

Kshs-------------
c) What is the cost of the ARV medicines that you take per months (if any)?

   None [ ]

   Kshs-----------------------

d) Do you lose any income as a result of your coming to the clinic?

   Yes [ ]

   No [ ]

   How much Kshs-----------------------

e) Do you incur any other costs as a result of your taking ARVs?

   Yes [ ]

   No [ ]

   How much Kshs-----------------------

f) What have you and/or your family had to give up in order to be able to take your medicines regularly?

   ………………………………………………………………………………………………………………………………………………………………………

   ………………………………………………………………………………………………………………………………………………………………………

8. QUALITY OF CARE

(a) What do you think of the service you receive at this clinic?

Do you feel listened to?

   Yes [ ]

   No [ ]

   Explain……………………………………………………………………………………………………………………………………………………………………

   Are you given the chance to state your problems and ask questions?

   Yes [ ]
No [ ]

Explain

Are you treated with respect?

Yes [ ]

No [ ]

Explain

Do you feel you can trust the health workers?

Yes [ ]

No [ ]

Explain

Do you have privacy during consultation and counselling?

Yes [ ]

No [ ]

Explain

How do you find the environment of the clinic?

Excellent [ ]

Good [ ]

Bad/poore [ ]

(b) How long did you spend altogether at the clinic when you last went for review?

Less than 1 hour [ ]

1 to 2 hours [ ]
(c) How long did you have to wait before being attended to?

Less than 30 min  [  ]

30 min to 1 hour  [  ]

More than 1 hour  [  ]

8. PERCEIVED PROBLEMS AND POSSIBLE SOLUTIONS

a) What do you perceive as the biggest problem regarding taking ARV treatment? ......................................................

b) What do you think could be done to improve this?

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

Thank you for your time and co-operation!
## APPENDIX II - STRUCTURED INTERVIEW WITH HEALTH WORKERS

<table>
<thead>
<tr>
<th>Name of facility:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Name interviewer</td>
<td></td>
</tr>
<tr>
<td>Interview number:</td>
<td></td>
</tr>
<tr>
<td>Date:</td>
<td></td>
</tr>
</tbody>
</table>

*Introduction of the interviewer(s), introduction of the study*

### 1. BACKGROUND INFORMATION ON INFORMANT (HEALTH WORKER)

#### a) Sex

- Male [  ]
- Female [  ]

#### b) Age (years)

- Below 25 years [  ]
- 25 to 30 [  ]
- 30 to 35 [  ]
- 35 to 40 [  ]
- Over 40 years [  ]

#### c) Profession

- Medical doctors, [  ]
- Nurses, [  ]
- Counsellors, [  ]
- Pharmacists, [  ]
- Social workers) [  ]
- Others (Specify) [  ]
d) For how long have you been involved in the programme?

- Less than 6 months  [  ]
- 6 months to 1 year  [  ]
- 1 to 2 years  [  ]
- More than 2 years  [  ]

2. TASKS AND TRAINING

a) Have you received any training specifically for this job?

- Yes  [  ]
- No  [  ]

If yes, What specific training have you received for this job in relation to ARV Programme?

<table>
<thead>
<tr>
<th>Type of training</th>
<th>Where (Institution)</th>
</tr>
</thead>
<tbody>
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</tbody>
</table>

b) Do you think this training has been sufficient? (Details)

- Yes  [  ]
- No  [  ]

3. DRUGS, TREATMENT AND PROCEDURES

a) Which treatment guidelines for HIV/AIDS management do you use at this facility?

- National guidelines  [  ]
- Others (Specify)  [  ]
b) Are the drugs you prescribe always available?

Yes [ ]

No [ ]

If not, give details – how often

Rarely [ ]

Always [ ]

What are the reasons for this lack of drugs

No supplies [ ]

No money to purchase [ ]

Bureaucracy in procurement [ ]

Others – Specify [ ]

What do you do incase the drugs you prescribe are not available

Ask the patient to come later [ ]

Ask the patient to buy else where [ ]

Change to another regimen [ ]

Others – Specify [ ]

d) Have you had periods where your patients have not been able to get their medications because they were not available in stock?

Yes [ ]

No [ ]

e) How reliable are your lab and diagnostic support services (for CD4, Viral load etc)?
Very reliable [   ]
Reliable [   ]
Not reliable [   ]
Don’t know [   ]

Do results come in on time?
Yes [   ]
No [   ]

f) What kind of information do patients receive when they begin ARVs?

<table>
<thead>
<tr>
<th>Type of Information</th>
<th>Yes</th>
<th>No</th>
<th>If Yes, By whom</th>
</tr>
</thead>
<tbody>
<tr>
<td>The disease process (i.e. HIV and AIDS)</td>
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<td></td>
<td></td>
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<tr>
<td>How the disease affects the body</td>
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<tr>
<td>How ARVs work</td>
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<td></td>
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<tr>
<td>How to use them</td>
<td></td>
<td></td>
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<tr>
<td>The need to continue treatment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What to do if a pill is forgotten</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Possible interactions with other drugs (including traditional medicines)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Which side effects can occur</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>What to do if they occur (Breast) feeding requirements</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>When and where to get re-supply</td>
<td></td>
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</tr>
</tbody>
</table>

4. ADHERENCE ISSUES

a) Generally speaking, do your patients keep their appointments?

Yes [   ]

No [   ]

b) How do you think your patients do, generally speaking, in terms of adherence to ART?
Excellent [ ]
Good [ ]
Bad [ ]

c) Could you estimate the percentage of your patients who you think are “sufficiently adherent” to ART?
Less than 50% [ ]
50% to 75% [ ]
100% [ ]
d) What do you use to determine adherence
Appointments [ ]
Refills [ ]
Other – Specify [ ]
e) What strategies are in place to support adherence?
…………………………………………………………………………………………
…………………………………………………………………………………………
j) What are the main challenges you face in supporting your patients to adhere to ARV drugs (especially for longer term users)?
…………………………………………………………………………………………
…………………………………………………………………………………………

5. CHALLENGES AND STAFF SUPPORT

a) What are the main challenges you and your colleagues face more generally in your work?
Workload [ ]
Stress [ ]
Burnout [ ]

b) Have you ever been afraid of being infected with HIV through your work?
   Yes [ ]
   No [ ]

Do you take any extra precautions when working with the patients?
   Yes [ ]
   No [ ]

c) Have these challenges changed in any way since you started working at the ARV clinic?
   Yes [ ]
   No [ ]

d) Is any special support made available for staff engaged in management of HIV/AIDS at this facility?
   Yes [ ]
   No [ ]

If no, what support do you think there is a need to have?

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


e) Is there anything you would like to see done differently in this facility?
   Yes [ ]
   No [ ]

If yes, what?
Thank you very much for your participation in this interview.
APPENDIX III. FOCUS GROUP DISCUSSION (FGD) FOR ART USERS

Requirements

• Participants per FGD (6 -8)

• Adults (= or >18 years, men and women separately – may want also to split into high - and low -adherers, if easily identifiable, depending on what country teams want to do)

• One moderator, one note-taker (and use of tape recorder)

• Neutral venue outside the facility

• Two FGD per facility (one with men and one with women)

Short introductory remarks

• Introduction of researchers and participants

• Thank participants for agreeing to participate, all share a common feature – they are on ARV treatment, are here to share their thoughts about ARVs and difficulties in taking ARVs: we want to learn from participants

• Explain purpose of study, purpose of this discussion, reassurance about confidentiality, agree on rules.

TOPICS FOR DISCUSSION

1. What treatments do you know to be available for treating HIV? What is your opinion about these? (e.g. ARVs; herbs; traditional medicines; spiritual healing; prayers; and perceived benefit (s) of treatment).

2. What is your experience of ART? (probe about adherence, adverse effects, pill burden, lack of food, lifestyle issues).
3. How do you think you are being treated (handled) by the health care workers (probe: privacy, confidentiality, respect, being listened to, time spent with patient, waiting time, integration with other services). What is the quality of care provided by health care workers?

1. What do you think about the counselling that you receive? (probe especially on importance of adherence effectiveness of counselling). What support are you given by the health workers to help you adhere better to your medications? Have you disclosed?

2. What support is available for you in the community, in the family, in the workplace? (probe about discrimination, stigma). Probe differences in perceived availability of social support versus social networks? Any negative social support? Any stress exacerbation?

3. What do you think could be done to help people adhere more easily to their Treatment? What do you think are the key reasons for non-adherence and good adherence? What are the sources of motivation for adherence?

4. What are you fertility and Reproductive health needs now that you are HIV positive. What options do you have incase you still need to have children. Explains

5. What do you think are the sexual needs of the people living with HIV and AIDS. Do you still have sex? Can this lead to any problem?
APPENDIX IV: ETHICAL CLEARANCE LETTER FROM MINISTRY OF SCIENCE AND TECHNOLOGY

REPUBLIC OF KENYA

MINISTRY OF SCIENCE & TECHNOLOGY

Telegrams: “SCIENCE TEC”, Nairobi
Telephone: 02-318581
E-Mail: ps@scienceandtechnology.go.ke

When Replying please quote
REF: MOST13/001/37C/689/2

JOGOO HOUSE "B"
HARAMBEE AVENUE,
P.O. Box 9583-00290
NAIROBI

John Paul Oyore
Kenyatta University
Department of Public Health
P.O Box 43844-00100
Nairobi

Dear Sir,

RE: RESEARCH AUTHORIZATION

Following your application for authority to conduct research on – Determinants of anti-retroviral Therapy access, adherence and High Risk behavior among People Living with HIV and AIDS in selected treatment sites in Nairobi, Kenya.

This is to inform you that you have been authorized to conduct research in selected treatment sites in Nairobi for the period ending 30th October 2009.

You are advised to report to the Provincial Commissioner, Provincial Director of Education and Provincial Medical Officer of Health before embarking on your research. On completion you are expected to submit two copies of your research report to this office.

Yours faithfully,

M. O. Ondiek
FOR PERMANENT SECRETARY

C.c. Provincial Commissioner - Nairobi
Provincial Director of Education - Nairobi
Provincial Medical officer of Health - Nairobi
APPENDIX V – RESEARCH PERMIT FROM FAMILY HEALTH OPTIONS KENYA.

FAMILY HEALTH OPTIONS KENYA
Family Health Plaza
Mai Maihi Rd., Nairobi West
P.O. Box 30801-00100
Tel: +254-20-601923/7, +254-20-604296/7
Mobile: +254-722-203871 / 734-609186
Fax: +254-20-603928
NAIROBI - KENYA
Email: info@fhok.org website: www.fhok.org

25th March 2008

Mr. John Paul Oyore
Kenyatta University
Dept of Public Health
P.O. Box 43844-00100
NAIROBI

Dear Sir,

RE: REQUEST TO CONDUCT RESEARCH WORK IN OUR FACILITIES

This is to inform you that your request to use some of our facilities to conduct a study entitled "Determinants of HIV – Antiretroviral Therapy Adherence and High Risk Behaviour among selected sites in Nairobi" has been granted.

The organisation expects you to observe ethical standards required of such work. You are required to work within the clinic protocol and consult with the respective managers.

We wish you success in your study.

Yours sincerely,

DR. LAWRENCE OTEBA
FOR EXECUTIVE DIRECTOR

cc: MCM Nairobi West FCMC
    MCM Thika FCMC
    MCM Ribeiro FCMC

Your Health, Our Concern
APPENDIX VI: RESEARCH PERMIT

This is to certify that:
Prof/Dr/Mt./Mrs./Mist. JOSH PAUL OTORKE

of (Address): DEPT. OF PUBLIC HEALTH,
KENTATA UNIVERSITY, P.O BOX 43844, KIBI

has been permitted to conduct research in:

Location, NAIROBI
District, NAIROBI
Province,

on the topic: DETERMINANTS OF ANTIRETROVIRAL THERAPY (ART) ADHERENCE AMONG HIGH RISK POPULATION LIVING WITH HIV/AIDS IN SELECTED TREATMENT SITES IN NAIROBI

for a period ending 30th October, 2009.

Research Permit No. 2003/13/001/371/369
Date of issue 15/10/2007
Fee received Kshs. 1,000

[Signature]
Ministry of Science and Technology

[Signature]
[Name]
Minister of Science and Technology

[Signature]
[Name]
Permanent Secretary
APPENDIX VI: ABSTRACT FOR SCIENTIFIC PAPER SUBMITTED FOR PUBLICATION

DETERMINANTS OF ADHERENCE TO ART AMONG PATIENTS ATTENDING PUBLIC AND PRIVATE HEALTH FACILITIES IN NAIROBI, KENYA.

JP Oyore¹, Bsc, MPH, ASS Orago ², PhD, IJ Mwanzo ¹, PhD, GW Odhiambo-Otieno ¹,PhD.
1. Department of Public Health, Kenyatta University, P.O Box 43844-00100, Nairobi, Kenya.
2. Director, National AIDS Control Council. P.O Box 61307-00200 , Nairobi, Kenya

Request for reprint to: John Paul Oyore, P.O Box 558-00100 Nairobi

DETERMINANTS OF ADHERENCE TO ANTI-RETROVIRAL THERAPY (ART) AMONG PATIENTS ATTENDING PUBLIC AND PRIVATE HEALTH FACILITIES IN NAIROBI, KENYA.

JP Oyore, ASS Orago, I Mwanzo and GW Odhiambo-Otieno

ABSTRACT
Background: Maximum suppression of the multiplication of the HIV virus and subsequent increase in the CD4 cell count a level of adherence of 95% and above in required among the patents on Antiretroviral Drugs (ARVs). Most patients on ART in Nairobi are not achieving the optimum adherence level required to maintain treatment efficacy, hence the risk of drug resistance and increased burden in the public health care system.

Objective: To identify the factors that influence adherence to ART among HIV patients attending public and private health facilities in Nairobi, Kenya.

Design: Non –interventional cross-sectional study using both qualitative and quantitative data collection methods.

Setting: Public and Private Health facilities offering ART in Nairobi

Subjects: Four hundred and fifty People Living with HIV and AIDS (PLWHA) receiving ARVs in selected public and private health facilities in Nairobi between June 2007 to June 2008

Results: Most patients do not have accurate knowledge of HIV and ARVs. The composite adherence ART level of adherence among patients in Nairobi was found to be 85%. The major factors that were found to constrain adherence were costs, lack of social support, side effects, time to reach the health facility, adequate knowledge of ARVs

Conclusions: In conclusion this study found out that majority of the patients on ART in Nairobi are not achieving optimum adherence. The major factors that lead to the sub-optimal adherence are lack of social support, lack of disclosure that one is taking ARVs, poor knowledge of ARVs, Associated costs such as transport and extra food requirements and the existence of side effects.

Recommendations: The health facilities offering ART should employ adequate numbers of well trained staff as this will help cope with increasing workloads in the ART clinics and it will also help reduce the long waiting times. There is also need to train staff in adherence counseling and continuously update their knowledge of HIV and AIDS, as this will help all the staff in the ART facilities to be able to participate in adherence counseling rather than leave it to the pharmacists only. Also, there should be Sustained community mobilization
aimed at mitigating stigma and discrimination in an effort to create an environment in which people can disclose and take their ARVs without fear of discovery.