# FACTORS INFLUENCING ADHERENCE TO ANTIRETROVIRAL MEDICATIONS AMONG PATIENTS LIVING WITH HIV IN KENYA

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**DECLARATION**

This project paper is my original work and has not been submitted for a degree in this or any other university.

…….. ……..

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This project has been submitted for examination with my approval as the supervisor.

…… ……

**Prof. CHARLES NZIOKA** Date

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**ACRONYMS**

**AIDS –** Acquired Immune Deficiency Syndrome

**ART –** Antiretroviral Therapy

**ARVs –** Antiretroviral medications

**CD4** - Cluster of Differentiation 4

**CDC** – Centre for Disease Control and Prevention

**ERC** – Ethics Review Committee

**HAART** - Highly Active Antiretroviral Therapy

**HCW** – Health Care Workers

**HIV –** Human Immune deficiency Virus

**KNH**- Kenyatta National Hospital

**PEPFAR** – US President's Emergency Plan for AIDS Relief

**PLHIV –** People Living With HIV

**UON** - University of Nairobi

**WHO** – World Health Organization

**ABSTRACT**

Although evidence suggests adherence to antiretroviral therapy (ART) in African settings is relatively high compared to North American settings, there are potentially high rates of loss-to-follow up and little evidence-based information regarding facilitators and barriers to adherence from developing countries yet majority of the people living with HIV and in need of ART come from this region. This study explores factors that facilitate adherence to ART medications among patients receiving antiretroviral medications from a clinic in Nairobi, Kenya.

The study used methodological triangulation with a sample of 277 patients systematically selected and interviewed using a structured questionnaire. A sub-sample of 22 patients was further selected to participate in the semi-structured interviews and a focus group discussion was conducted with 9 health care providers. Patients' adherence levels were determined using monthly pharmacy pill counts and a multivariate regression model was used to determine predictors of adherence.

Out of the 277 respondents interviewed 72% (200) were female and 28% (77) were male. The median age of the respondents was 35 years and 91% (228) of the patients on ART achieved perfect adherence (>95%). Level of income (p-value 0.023 and odds ratio 4.093) and use of memory aids (p-value 0.016 and odds ratio 4.864) predicted optimal adherence. Five factors emerged to explain optimal adherence: 1) improved health status after ART initiation; 2) faith in the drugs (patients referred to drugs as food or life) resulting in making drug taking part of their daily routine; 3) having dreams to accomplish and meet family obligations; 4) support from others such as treatment buddies, health care providers and support groups and 5) use of reminder tools.

Level of adherence using pharmacy pill count was high, with 91% of the patients achieving perfect adherence of 95% and above. Adherence to treatment requires team work between patients, health care providers and policy makers. Although adherence was

high in this group, it can further be improved. At the individual level, patients need to assess the motivators and barriers to adherence. This will help them to develop positive attitude towards adherence and deal with the barriers encountered. At the facility level, the health care providers have the obligation to ensure high health literacy levels among patients through intensive adherence counseling before and after ART initiation. At the policy level, policy makers should review empirical research focusing on interventions to improve adherence and come up with evidence-based recommendations to improve adherence.

# CHAPTER ONE

# INTRODUCTION

## 1.1 Background

Sub-Saharan Africa is home to 23 million adults and children living with HIV/AIDS (WHO, UNAID & UNICEF 2011) and the introduction of Highly Active Antiretroviral Therapy (HAART) has reduced morbidity and mortality among people living with HIV leading to HIV/AIDS being regarded as a chronic disease and the resultant rapid scale up of ART rollout in the region (Hammer et al., (2006).

High level of adherence to antiretroviral medication is essential to minimize treatment failure and disease progression. The aim of antiretroviral therapy is to keep the HIV viral load at undetectable levels for as long as possible and to maintain the functionality of the immune system (Yeni et al., 2004)

Poor adherence and treatment interruptions are the main reasons for failure of ART suppressing HIV viral load leading to drug resistance. ART adherence levels of 95 percent are necessary to achieve and sustain suppression of viral load (Paterson et al., 2000). Studies have found a strong relationship between levels of adherence to antiretroviral therapy and risk of progression to AIDS; hence failure to obtain scheduled pharmacy refills is associated with a rapid progression to AIDS and death. Evidence shows that for every 10 percent decrease in adherence, there is a 16 percent increase in HIV related mortality (Bangsberg et al., 2001; Hogg R, 2000).

Some of the factors associated with poor adherence include; fear of disclosure, depression, side effects, disruption of daily routine, social isolation, financial constraints and travel cost to get access to treatment. Facilitators of adherence include; faith in how well the drugs work, using reminder tools and trusting relations with health-care providers (Mills et al., 2006).

The benefits associated with adhering to ARVs are recovery of immunity hence ability to fight opportunistic infections, improved quality of life allowing patients to become strong and healthy and able to get back to work. Also ARVs are associated with delay in disease progression to AIDS, reducing viral load and decline in morbidity and mortality in people living with HIV. On the other hand suboptimal adherence is associated with treatment failure, viral mutation and development of drug-resistance HIV. This might reverse the initial benefits accrued from optimal adherence.

This study explores factors that facilitate adherence to ART medications among patients living with HIV and identifies and recommends possible interventions to improve ART adherence. The benefits of optimal adherence have been outlined above and also the disadvantages of sub-optimal adherence. It is of paramount importance to ensure that patients adhere to their drug regimen as indicated above and also that they stick to the first line regimen to minimize cost of care and treatment for PLHIV and also because the second line regimens are more complex in terms of fitting them into the patients daily activities and lifestyle and also because the drugs are more expensive. Recent findings show that viral suppression can significantly prevent new HIV infection (Cohen et al., 2011).

### 1.2. The Problem Statement

Globally there are 34 million people living with HIV and two-thirds of them are from Sub-Saharan Africa (WHO, UNAID & UNICEF 2011). Over 6 million people are accessing antiretroviral medications and it is paramount for them to adhere well to the drugs to maximize treatment effect (WHO, UNAID & UNICEF 2011).

In 2005, Kenya scaled up antiretroviral medication making access to HIV care much easier than the previous years. With the antiretroviral therapy (ART) roll-out, patient adherence is an issue that has generated a lot of interest. With the lack of a cure for HIV, ART is the only available option that can reduce HIV-related morbidity and mortality, improve patients' health status and quality of life. However an adherence rate of 95% and above to the prescribed drugs is required. Evidence shows that adherence to long term

therapies in resource limited countries averages 50% and that poor adherence to these long term therapies leads to poor health outcomes and high health care costs (Sabaté, 2003).

Since adherence plays an important role for the success of ART, a number of studies have been conducted on the factors that influence adherence. Majority of these studies have been conducted in the developed nations, while studies in low income countries and especially sub-Saharan Africa which bears the heaviest burden of HIV are limited (Mills et al., 2006). In addition most of the studies conducted are of quantitative nature and rarely use mixed methodology to study adherence issues in Africa.

The 2010 UNGASS report estimates ART coverage among adults in Kenya to be 70.4% with 336,980 people on ART by end of 2009 (NASCOP, 2010) . As ART services are scaled up in Kenya and Africa, we need to create a knowledge hub about patients' experiences adhering to antiretroviral medications. The aim of this study is to fill the knowledge gap on facilitators and barriers to adherence and recommend possible interventions to improve adherence. First the study determines the adherence levels of the respondents; second it assesses the knowledge and perception of the respondents regarding HIV and ART and finally identifies motivators and barriers to adherence to antiretroviral medications. This information will build on the understanding of appropriate interventions that can support and maintain adherence and ensure achievement of the benefits of ART such as improved health status and decreased health care costs since adherent patients will be maintained on the less expensive first line drugs.

### 1.3. The rationale of the study/ justification

A systematic review of barriers and facilitators of adherence in developing and developed countries revealed that very little evidence based information regarding these factors is available from developing countries yet majority of the population living with HIV and in need of antiretroviral medication come from this region (Mills et al., 2006).

This study identified and explored these issues hence providing relevant information to health care workers and policy makers on areas that require emphasis to ensure optimal HAART adherence. The study also measured the adherence rates of patients taking antiretroviral medications.

### 1.4. Research questions

1. What proportions of patients adhere to antiretroviral medications?
2. What is the knowledge and perception of patients regarding HIV and ART?
3. What factors motivate or discourage adherence to antiretroviral medications?

### 1.5. Hypothesis

- The null hypothesis – There are no factors which influence adherence to antiretroviral medications.
- Alternative hypothesis – High adherence to ART is influenced by factors such as socio-demographic attributes, knowledge and perceptions on HIV and ART, patient social behavioral characteristics and ART service delivery environment.

### 1.6. Objectives of the study

To explore facilitators and barriers to antiretroviral medications adherence and recommend possible interventions to improve adherence

#### 1.6.1. Specific objectives

1. To determine the adherence levels among the PLHIV
2. To determine the knowledge and perception of HIV and adherence to ARVs among the PLHIV.
3. To identify and explore motivators of and barriers to adherence to antiretroviral medication

### 1.7. The scope and limitations of the study

The study focus is on adherence to antiretroviral medications among patients attending the University of Nairobi Pumwani HIV Comprehensive Care Clinic, specifically adults taking antiretroviral medications for a duration of not less than one month. While concentrating on adherence the study assesses the level of knowledge and perception on HIV and ART, measures adherence levels of the patients and identifies major factors that may affect adherence to antiretroviral medications.

The study may have been limited by the recruitment strategy used which did not factor in patients who may have dropped out of the ART program. These patients could have shed more light on the barriers to ART adherence. Also the recruitment strategy missed those patients that were not scheduled for appointments during the recruitment period. This may have resulted in over estimation of the adherence rate in this study.

While collecting data on knowledge and perception on HIV and ART, no data was collected on attitude towards ART adherence which could have shed more light on why patients choose to adhere or not adhere to ART.

During the key informant interviews with the patients, having a sense of obligation to the family was cited as a motivating factor that improved adherence yet no data was collected regarding the family size of the respondents.

### 1.8. Definition of terms

**Adherence**: The ability of a patient to take all the medications prescribed in the right way, right time and right dosage.

**ARV:** The term refers to antiretroviral HIV drugs and it is drug used to prevent a retrovirus such as HIV from replicating

**ART (Antiretroviral Therapy):** It involves using a cocktail of three or more antiretroviral (ARV) drugs to prevent HIV from replicating and it is the recommended treatment for HIV infection.

**CD4:** A molecule on the surface of some cells of the immune system onto which HIV can bind. HIV weakens the immune system by destroying CD4 cell. The CD4 cell count reflects the state of the immune system

**Defaulters:** Patients who fail to collect medication or honor clinic appointment for more than 7 days.

**Drug Resistance:** When a virus mutates and becomes less sensitive to a drug that was previously effective.

**HAART:** Stands for highly active antiretroviral therapy, also known as ART

**Loss to follow-up**: Patients who are lost from the continuum of care for a period of more than 3 months

**Optimum/perfect adherence:** Perfect/Optimum adherence means having an adherence level of 95% and above. If one is taking once daily treatments it means missing no more than one dose per month, if it's a twice daily treatment it means missing no more than three doses per month and if one is taking three times a day treatment it means missing no more than four doses per month.

**Undetectable Viral Load:** When the amount of HIV in the blood is too low to be detected with a viral load test which measures the amount of HIV in a sample of blood

**Viral Load:** The amount of HIV in a sample of blood. One of the main goals of ART is to suppress the viral load to an undetectable level

**Retention:** Ensuring that the client consistently continues to receive appropriate services throughout the continuum of HIV care and support.

# CHAPTER TWO

# LITERATURE REVIEW

This section presents a review of the literature and will focus on the HIV/AIDS situation, antiretroviral therapy, factors affecting adherence to ART and measurement of adherence levels.

## 2.1. History of HIV and AIDS

The human immunodeficiency virus (HIV) was discovered in 1983 (WHO, UNAIDS & UNICEF 2003), and it is responsible for the development of the acquired immunodeficiency syndrome. HIV attacks the immune system cells, thereby weakening the immune system and making the body vulnerable to opportunistic infections leading to AIDS.

### 2.1.1. Global situation

According to the World Health Organization, 2011 progress report global HIV/AIDS response, the number of people living with HIV/AIDS globally by the end of 2010 was 34 million people, people newly infected by HIV was 2.7 million people and AIDS related deaths in 2010 was 1.8 million people. The number of people receiving antiretroviral medication in low and middle income countries was 6.65 million people. Improved access to treatment has an impact in lowering the number of AIDS related deaths. Antiretroviral therapy coverage was reported to rise from 7% in 2003 to 47% in 2010 (WHO, UNAIDS & UNICEF 2011).

### 2.1.2. Sub-Saharan situation

By end of 2010, the number of people living with HIV/AIDS was 22.9 million, people newly infected by HIV were 1.9 million and number of AIDS –related deaths was 1.2 million. Sub-Sahara Africa accounted for 68% of world's HIV infections and 70% of all new infections globally. By the end of December 2010, 49% (5 064 000) of people in need of antiretroviral therapy were receiving treatment. Expanded antiretroviral medication access decreases the number of people dying from HIV-related causes. The

1.2 million AIDS related deaths in 2010 are reported to be 29% fewer than 2005 ( WHO, UNAIDS & UNICEF 2011).

### 2.1.3. HIV and AIDS in Kenya

The 2007 Kenya AIDS Indicators Survey estimated that 1.4 million Kenyan were living with HIV, with a prevalence of 7.4% among people aged 15-65 years (KAIS, 2009). ART coverage in Kenya increased from 42% (172,000) in 2007 to 70.4% (336,980) in 2009 (UNGASS, 2010). According to the National AIDS/STI Control Program (NASCOP) at end of December 2010, the estimated number of patients on ART was 462,005 and over 900,000 patients were on HIV care. Due to increased access of ART by 2010 AIDS related deaths dropped from 120,000 in 2003 to 85,000 hence AIDS-related deaths have also fallen by 29% (NASCOP, 2010).

## 2.2. Antiretroviral therapy

Although highly-active antiretroviral therapy (HAART) is not curative, lifelong treatment with ART reduces mortality and improves quality of life among people living with HIV/AIDS. The antiretroviral drugs normally suppress the replication of the virus in the body, and are used to treat and prevent HIV infection.

ART is a lifelong commitment which requires patients to adhere well to daily medications dosing schedules and frequent clinic visits for care and ART refill. Patients who fail to adhere well or discontinue treatment are at risk of drug resistance leading to illness and death due to AIDS related conditions. A non-adherent patient on antiretroviral therapy is 3.87 times more likely to die than an adherent patient on the same therapy (Garcia de Olalla et al., 2002).

ART is expensive but access to HIV care and antiretroviral drugs in Sub-Saharan Africa has improved tremendously in the last ten years due to major efforts by various governments, international organizations and funding bodies. Early meta-analysis findings about adherence to ART in sub-Saharan Africa found that a pooled estimate of 77% of patients in African settings achieved adequate adherence (95% of prescribed

pills), compared with 55% of patients in North American settings (Mills et al., 2006). However, adherence still poses a challenge amongst resource limited settings since there is still evidence of high rates of patient loss-to-follow up.

A review of 33 patient cohorts totaling 74,289 patients in 13 countries suggested that ART programs in Africa retain only about 60% of their patients after two years on ART. Loss to follow-up and death were cited as the main cause of the poor retention. The study suggests that patients should be started on ART earlier before they get seriously ill to reduce deaths due to HIV related illnesses and that programs should attempt to find out why patients drop out of the ART programs and don't come back for ART refills (Rosen et al., 2007). These findings also suggest that we need a better understanding of patients' experiences on ART and what motivates or hinders adherence to ART and retention in care.

Some of the interventions to improve patient retention and adherence to ART include pretreatment and ongoing counseling, medication diaries, pill boxes, buddy system (ART assistant) electronic devices (pagers, alarms, text reminders) and providing incentives (food, transport among others).

### 2.3. Factors affecting adherence to ART

Some of the factors affecting adherence to ART include:

#### 2.3.1. Financial constraints

Financial constraints such as cost of drugs and/cost of transport to the health facilities have been cited as an obstacles to optimal adherence to ART and retention of patients in ART programs (Hardon et al., 2007; Laurent et al., 2005; Weiser et al., 2003). A study in Botswana that assessed barriers to ART adherence found that adherence using patient self report was 54%. The cost of ARVs was a significant barrier to adherence in the study and it was predicted that if cost was removed as a barrier, adherence would increase from 54% to 74% (S. Weiser et al., 2003). The study was conducted before the roll-out and scale up of free ARVs in the public sector. Currently, almost all public sector facilities in

developing nations provide free ARVs. Despite the provision of free ARVs, patients have other related costs such as transport and lost wages due to long waiting times at the HIV care and treatment facilities (Hardon et al., 2007).

### 2.3.2. Food insecurity and hunger

A study conducted in Uganda indicates that food insecurity and hunger may interfere with adherence and that these two factors may cause people to delay being started on ART or to discontinue ART therapy. Some of the factors identified by the study as ways through which food insecurity affected ART adherence are increased hunger with ARVs, worse ARV side effects in the absence of food, counseling on the need to take ARVs with food, competing demands between food cost and healthcare expenses and forgetting or being unable to take ARVs while working ( Weiser et al., 2010) .

### 2.3.3. Distance from patients home to the clinic

A study on factors influencing non-adherence to ART in Nairobi Kenya found that non adherence among the respondents was 18%. Distance from patients' home to the clinic significantly predicted non-adherence. It was found that respondents who accessed HIV care and treatment in clinics within a walking distance to their homes were two-and-a half more times likely to not to adhere to ART than those who lived far away from the clinics (Wakibi et al., 2011). The possible reason given for that was due to fear of being stigmatized since these patients accessed care in the clinics near their homes because they did not have any other choice due to lack of transport to alternative clinics.

### 2.3.4. Disclosure and stigma

Other important barriers to adherence are fear of HIV status, disclosure or stigma, and medication side effects (Hardon et al., 2007; Weiser et al., 2003). Stigma is often related to issues of HIV status disclosure and has an impact on adherence because it makes it hard for patients to interrupt social situations for a scheduled dosage. Also, in households where partners may not have disclosed their status it is very difficult for patients to adhere well to the medications.

### 2.3.5. Lifestyle changes

The second factor identified as a predictor of non-adherence by the Wakibi (2011) study in Kenya was difficulties fitting the therapy in one's own daily schedule (Wakibi et al., 2011). This could be because ARVs are lifelong medications which need a daily commitment that entails taking drugs at specific times in the morning and evening. Failure to fit these drugs with one's daily routine can lead to non-adherence hence poor treatment outcomes.

### 2.3.6. Intensive counseling before HAART initiation

A study conducted in Nairobi to assess the effects of counseling and alarm device on HAART adherence and virologic outcomes found that early intensive adherence counseling when a patient is being started on HAART resulted in a significant reduction in poor adherence and virologic failure while use of alarm device had no impact (Chung et al., 2011). Intensive counseling of patients before and after ART initiation provides channels for improving communication and building rapport and trust between the clinician and patients. It also provides the patients with the necessary knowledge and education that is significant to adherence to ART and retention in the ART program.

### 2.3.7. Medication side effects

Medication side effects can lead to an individual refusing to take their medication. Some of these side effects include fat redistribution, severe diarrhea, vomiting and drug related allergies. Poor adherence can also be due to barriers pertaining to beliefs/perceptions about medications. These barriers include real or anticipated side effects, complicated regimes, taste, size, dosing frequency and/or pill count. A study in Italy assessed whether self reported symptoms and medication side effects have an effect on adherence and found that almost all the symptoms and medications side effects reported in the course of the study were more often by non-adherent persons (Ammassari et al., 2001).

### 2.3.8. Psychological factors

Psychological factors such as depression and perception of one's ability to follow a medication regimen (self-efficacy) may influence ART adherence. A study among HIV

positive youths shows that self efficacy and psychological distress are significantly correlated with adherence (Naar-King et al., 2006). Low self efficacy and mental health conditions such as depression may result in non-adherence. Evidence shows that adherent patients have better coping mechanisms and less depression (Singh et al., 1996).

Another study conducted in Nairobi and Central Kenya aimed at assessing whether coping self efficacy can influence adherence by using a 26-item questionnaire to measure ones confidence in performing coping behaviors once one is with life challenges. 94.5 % of the participants indicated that they had not missed any of their pills in the previous 4 days. Some of the reasons identified for missing doses were being busy, forgetfulness, not wanting others to notice patients taking medications, feeling sick and feeling they are fine. The study found that there was a significant relationship between coping self efficacy and adherence (Kamau et al., 2011). One's confidence in the ability to adhere to the medications may be enhanced by the ability to cope with stressors. For instance the perception that reminder tools may enhance the ability to take medications at the right time may result in adherent behavior among patients with adherence problems.

### 2.3.9. Socio-demographic characteristics

The role of socio-demographic characteristics such as gender, age and level of education have also been cited as predictors of adherence though there have been inconsistent results pertaining association of these characteristics with adherence (Ndayanga et al., 2005). This study will be able to compare these characteristics with ART adherence and report its findings.

## 2.4. Measurement of adherence rates

As previously discussed, there is a relationship between adherence to antiretroviral therapy and viral load, that is, as adherence levels decrease, viral load increases rapidly. Greater increase in viral load leads to progression to AIDS hence increase in HIV-related morbidity and mortality (Bangsberg et al., 2001; Paterson et al., 2000). This underscores the importance of measuring adherence levels in patients undergoing antiretroviral therapy.

Adherence is “the extent to which a person’s behavior – taking medication, following a diet, and/or executing lifestyle changes - corresponds with agreed recommendations from a health care provider” (Sabaté, 2003). Adherence to ART means:

- Taking all the antiretroviral medications prescribed in the correct quantities
- Taking all the pills at the right times
- Taking all the medications according to the instructions given by the medical personnel, that is either with or without food, according to dietary instructions.
- Checking for interaction of antiretroviral medications with other medications or drugs. This includes the medical personnel ensuring that the medicines prescribed to the patient do not interact with the antiretroviral medications. It also includes the patient ensuring that any drugs bought over the counter do not interact with the ARVs (AFAO, 2009).

An adherence of 95 percent and above has been described as one that can yield the best response to ART. This means it can result to maximum viral suppression, increase of CD4 cell counts, minimize risk of drug resistance hence prevent HIV disease progression, improve quality of life and prolong survival.

Adherence levels below 95 percent have been associated with poor viral suppression and lower increase in CD4 cell count. Failure to suppress viral replication completely leads to emergence of drug resistance strains limiting the effectiveness of antiretroviral therapy.

Some of the methods used in measurement of adherence include: self report techniques such as recall methods and visual analogue scale (VAS), pill count, electronic drug monitors, pharmacy records, computer-assisted self interviews (CASI), and biochemical markers such as viral load test which measures the amount of virus in an individual’s blood. This study used pill count methods which are easy to use and low cost to measure adherence levels of respondents.

Keeping scheduled clinic appointments can also be a cost effective way of assessing patients’ adherence to ART. A study on alternative ways of measuring adherence in Kenya and Zambia assessed whether keeping scheduled clinic appointments was

associated with adherence and risk of virologic failure. The adherence level reported in this study was 94 %. The common reason for not taking pills was forgetting, running out of pills and travelling. Findings from this study show that self reported adherence can be used as a method of measuring adherence since those participants who self reported non adherence were more likely to have been late for their clinic visit (Blacher et al., 2010).

## 2.5. Theoretical Model

### 2.5.1. Theory of planned behavior

This theory attempts to predict occurrence of behavior as long as that behavior is intentional. The theory develops on similar foundations as those of the theory of reasoned action whereby behavior is meant to be voluntary. Since behavior is not hundred percent voluntary and some various factors may control behavior, the perceived behavior control construct was introduced leading to the formulation of the theory of planned behavior (Ajzen, 1991).

Three perceptions serve as the main construct of the model: attitudes, subjective norms and perceived behavior control. Attitude towards the behavior refers to an individual's belief about the outcome of behavior and the evaluation of such an outcome. Subjective norm about the behavior refers to an individual's estimate of the social pressure to perform the target behavior, that is, belief about how significant others may expect them to behave. Perceived behavior control is the degree to which a person feels able to perform the behavior, that is how much an individual has control over the behavior and how confident one feels about being able to enact or not enact the behavior (Ajzen, 1991).

#### 2.5.1.1. Relevance of the theory to the study

An adherence level of 95% and above of the prescribed pills is expected among those taking antiretroviral medications. Regarding one's attitude towards a behavior, the belief that if one takes the prescribed pills they will feel better creates the positive attitude that can influence adherent behavior. Also when a patient keeps on evaluating the expected

outcomes of taking ARVs, which in this case is improved health outcome that also motivates the individual to continue adhering the medications.

Regarding the subjective norm towards a behavior, refers to the belief about how other people (and in this case this could be family members, treatment buddies and health care providers) would like an individual to adhere to the medications. So an individual feels the pressure to adhere to the medication since they want to do what other people expect of them. This pressure is also important in ensuring one forms a positive attitude that influences adherence.

Regarding the perceived behavioral control, this is where a patient on ART constantly remembers that adhering to the medications can be a difficult task and hence develops mechanisms of enhancing adherent behavior. For instance if an individual finds that they keep forgetting to take their medication, then they can control the forgetfulness by using reminder tools such as an alarm or can identify a treatment buddy to remind them to take their medications.

### 2.5.2. Rational Choice Theory

This theory attempts to explain behavior in terms of how individuals make choices under the influence of their preferences. The theory develops on similar foundations as those of the social exchange theory where all parties try to maximize their advantage or gain and to minimize their disadvantage or loss hence human beings base their behavior on rational calculations in order to optimize their pleasure or profit.

In rational choice theory, the value of a reward is the ‘utility’ it has for that person. Utility is an economic term referring to the total satisfaction received from consuming a good or service. In general, utility in someone’s behavior is seen in terms of such things as the amount of time that it takes up and the frequency with which they are able to do it (Scott, 2000).

The rational choice theory also recognizes that the threat of punishment or the promise of a reward may motivate people just as much as the punishment or reward itself. The threat of punishment, for example, may call forth appropriate behavior from those who wish to avoid the punishment.

#### 2.5.2.1. Relevance of the theory to the study

Patients on antiretroviral drugs are expected to adhere to the drugs in order to optimize the benefits of these drugs. According to the rational choice theory, this interaction will only continue if the patients find the drugs to be useful. If at any point the patient experiences a 'loss' then they find adherence to be more costly than rewarding and so will opt to skip medicines, miss clinic appointments or drop out of the treatment program. The adherence behavior is seen as an exchange of perceived costs (loss) and observed drug efficacy (profit).

In the context of this study, we would expect patients in an ART program to continuously engage in a calculus of rewards and costs and adherent behavior will only be achieved if they are making a 'profit'. Those who experience a 'loss' will withdraw and seek alternative profitable interactions. Hence if individuals feel that the ART program is costing them time, money and infringing on their lifestyle and social interactions they may not sustain the adherent behavior. Alternatively, if individuals experience benefits from the program such as improved health, the adherent behavior will continue.

### 2.5.3. Social Cognitive Theory

The Social Cognitive Theory was developed by Albert Bandura in 1986 (Bandura, 1989). It stresses continuous, dynamic interaction between the person, the behavior and the environment. It's core determinants includes, knowledge of health risks and benefits of different health practices, perceived self efficacy (that one can exercise control over one's health habits), the health goals people set for themselves and the concrete plans and strategies for realizing them and the perceived facilitators and social structural impediments to change they seek.

One of the major concepts of the social cognitive theory is self efficacy which is concerned with the role of the person within the reciprocal interaction described by the Social Cognitive Theory. This implies that accurate appraisal of one's capabilities has considerable value in determining behavior. How people judge their capabilities influence motivating or hindering thought patterns. Bandura identifies four principal sources of information that influence this judgement of self-efficacy. These include, mastery experiences (previous experiences of behavior), vicarious experiences (the experience you learn from observing others), verbal persuasion (persuasion from significant others) and psychological states from which people partly judge their capability, strength and vulnerability (Bandura, 1998).

#### 2.5.3.1. Relevance of the theory to the study

This theory helps us to understand the multifaceted causal structure of human action and in this case the human action is the adherent behavior. This study was able assess the personal traits such as the socio-demographics factors, knowledge and perception of the disease, and the medications and the psychosocial factors that come into play in influencing adherence. Other factors that were assessed are the clinical environment and the treatment-related factors. Hence by using this theory we shall employ a multidirectional perspective instead of a unidirectional one in understanding adherent behavior.

The concepts in this theory will inform the variables developed to understand the key factors that influence adherence behavior of individuals taking antiretroviral drugs.

When we look at the interaction between the person and behavior, Bandura notes that the reciprocal causation between the person and the behavior reflects the interaction between thought, affect and action. Hence what people think, believe and feel affects how they behave (Bandura, 1989). This study assessed the knowledge, attitude and behavior of the participants in regard to ART and HIV/AIDS and how this affects their adherence behavior.

According to Bandura, environmental influences partly determine which forms of behavior are developed and activated and on the other hand, behavior determines which of the many potential environmental influences will come into play and what forms they will take (Bandura, 1989). An individual's environment affects how they adhere to the medications. In this case we shall look at the clinical and the social environment. The clinical environment will assess how satisfied the participant is with the services he or she is receiving at the health facility and how this affects the adherence levels. The social environment will assess the support the individual receives from the significant others, other psychosocial issues such as depression, alcohol and substance abuse and spirituality.

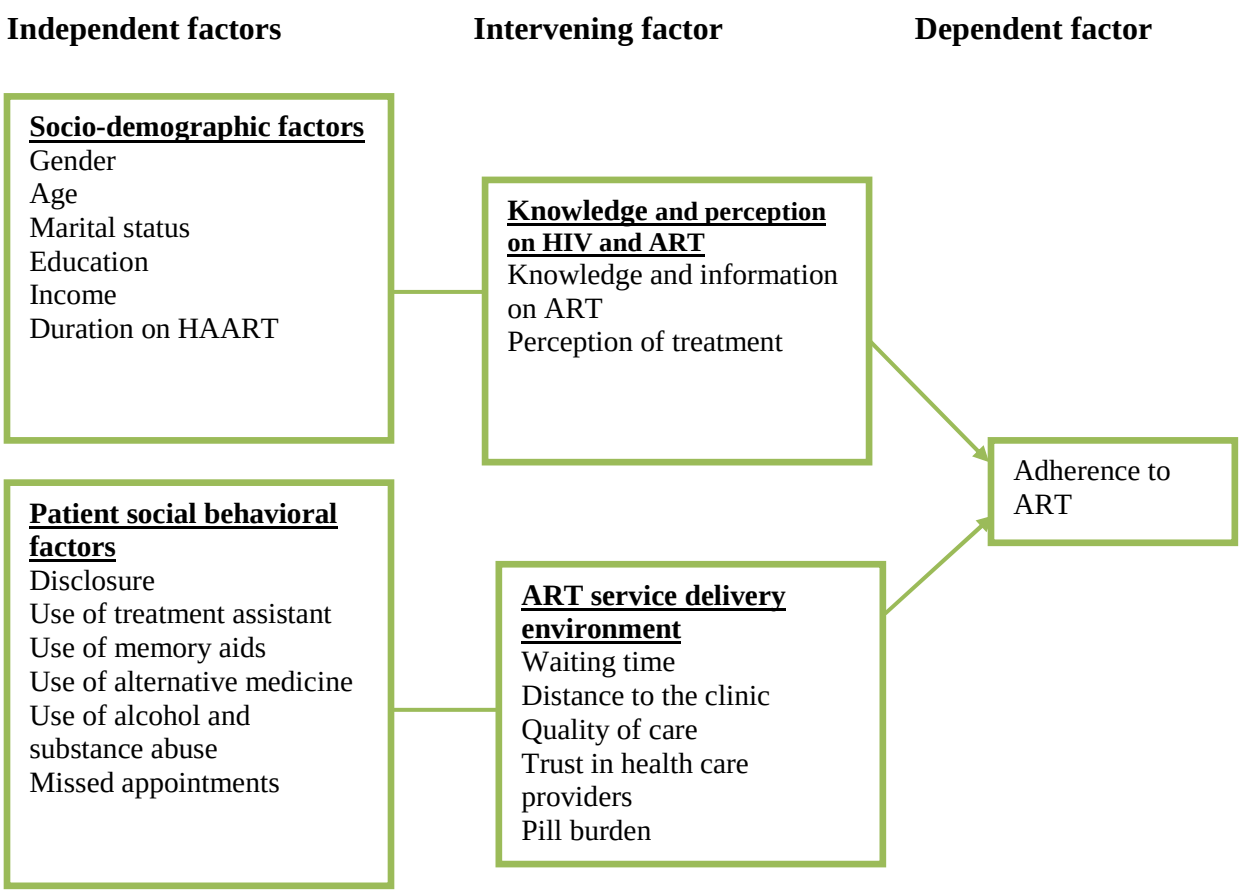
The concept of self efficacy is a mediating factor that influences how other factors affect adherence. For instance the belief that one is capable of adhering to the medications influences one's outcome expectation which in this case is the belief that if one takes their medication they will feel better. This is in terms of improving health outcomes such as increase in the level of immunity, viral suppression, increase in weight and other objective or subjective health outcomes. The belief in one's capability to adhere to the medication will also enable the participants to be able to identify factors that either motivate or hinder adherence to medication.

Social cognitive theory hence will be helpful in understanding and predicting adherent behavior and also in coming up with recommendations for improving adherent behavior.

### 2.5.4. Conceptual framework

The conceptual framework identifies patient related factors, ART service delivery environment and regimen related factors as independent variables, knowledge and perception on HIV and ART as intervening variables and adherence to ART as the dependent variable. This study investigated the above mentioned variables in order to identify factors that can be associated with adherence in the Kenyan context.

**Figure 1: Conceptual framework**



# CHAPTER THREE

# RESEARCH DESIGN AND METHODOLOGY

## 3.1. Study site description

The study was carried out at the University of Nairobi, Pumwani HIV Care and Treatment Clinic, which is situated in Pumwani division in Nairobi District. The clinic is run under the collaborative work of the universities of Nairobi and Manitoba and the HIV care and treatment program is funded by CDC PEPFAR.

By the time the study was being conducted Pumwani Clinic had a total of 3800 patients and a total of 1500 patients were on antiretroviral therapy (ART). The clinic is managed by one medical doctor, three clinical officers, seven nurse counselors, one counselor, one social worker and one receptionist. The patients provided primary data which was in the form of survey questionnaires and in-depth interviews while the health care workers participated in in-depth interviews. All study participants were required to give written consent indicating that they had understood the purpose of the study and had voluntarily agreed to participate in the study.

## 3.2. Study population

The study population was drawn from adult patients taking antiretroviral medication at the Pumwani clinic. The inclusion criteria was adults, aged 18 years and above on ART for at least one month and willing to participate in the study. This population was able to provide quantitative and qualitative data on factors that affect adherence to ART and also give recommendations on ways of dealing with adherence issues.

Additional data was collected from key informants who were selected from health care workers, that is, nurses, clinicians, counselors and social workers working at the Pumwani Clinic who had knowledge and experience in HIV care and management.

### 3.3. Methods of data collection

#### 3.3.1. Triangulation

This study used inter-method triangulation by combining use of surveys and in-depth interviews to generate a richer and comprehensive view of motivators and barriers to adherence to antiretroviral medication.

The researcher used methodological triangulation, which is defined by Duffy (1987) as the use of two or more methods of data collection procedures within a study. Duffy (1987) elaborates that methodological triangulation can take two forms: within method and between method. In within method triangulation the researcher takes one method such as the survey method and uses several strategies within that method to examine the data. The advantage of this approach is in checking the reliability of the quality of data though bias and validity threats are still possible. The between method triangulation is the use of data collected through more than one method. The researcher brings together data collected through quantitative and qualitative research methods in order to permit one type of data to elaborate the findings of another by providing richness and detail leading to a complete understanding of the phenomenon under study; and neither necessarily takes precedence over the other (Duffy, 1987).

The basic assumption in the use of triangulation is that the weakness in each single method will be compensated by the counter-balancing strengths of another (Rohner, 1977). In this case the survey questionnaires will yield data that can be measured and hypothesis that can be confirmed by measurement. The researcher will be able to measure the adherence rates of the participants and use these adherence rates to come up with predictors of adherence. On the other hand, the in-depth interviews will focus on key informants who have experience and knowledge of adherence to antiretroviral medications thus have firsthand experience on adherence matters and can provide a holistic view of the subject being studied. In-depth interviews are also flexible allowing the researcher to explore and discover issues that might not be discussed in details during survey interviews due to their highly structured nature.

Quantitative data was collected from HIV positive adults on ART and receiving care and treatment at Pumwani Clinic while qualitative data was collected from key informants who were ART patients and health care workers at the clinic.

### 3.3.2. Specific method of data collection

The specific method of data collection used in this study included survey and in-depth interviews. The questionnaires were also pretested before the commencement of data collection to determine their effectiveness. Below is a description of each method.

#### 3.3.2.1. Survey interviews

The first phase of the study included survey interviews which were administered to adult patients on ART who attend Pumwani Clinic to determine the knowledge, attitude and behavior of the patients in regard to ART adherence, factors affecting adherence and measurement of adherence levels among the patients. The adherence levels were measured using one-month pharmacy pill counts.

The main reason for using surveys is that they allowed the researcher to measure adherence rates at the clinic, capture factors affecting adherence, measure adherence levels and assess whether there is a relationship between adherence levels and factors such as socio-demographic characteristics, knowledge, attitude and perception of ART, psychosocial factors, treatment related factors and clinical environment.

The advantage that survey interviews have over in-depth interviews is the ability to use statistical methods to measure and quantify adherence to antiretroviral medication and generalize the findings to the general population in the health facility.

The survey interviews were able to explain causality between the different variables being studied and at the same time come up with predictive factors affecting adherence to antiretroviral drugs.

#### 3.3.2.1.1. Sample size

The sample size was determined using Fisher's exact test. The assumption is that the sample will be representative, the sampling error will be small and that the results will be generalizable.

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

Where z= standard variate (1.96) which corresponds to 95% confidence interval

p= proportion of estimated patients in African settings who achieved adequate adherence, that is, 95% of prescribed pills (Mills, Nachega, Buchan, et al., 2006).

q=1-p

p=0.77

q=0.23

e=0.05

$$n=\frac{1.96^2 \times 0.77 \times 0.25}{0.05^2}$$

n= 272

#### 3.3.2.1.2. Sampling technique

The study used systematic sampling with a random start to select the respondents that were interviewed using the survey questionnaire.

The researcher's experience working at the Pumwani clinic served as an entry point to the clinic and helped in making an informed decision on the sampling procedure and on the number of participants that could be interviewed per day.

The clinic uses an electronic patient register and appointment monitor which captures patient appointment scheduling in terms of past, current and future clinic visit types. This study was interested in patients scheduled for ARVs refill and used the electronic patient register as a daily sampling frame to help come up with the sampling interval and starting point.

In the systematic random sampling technique, the researcher first calculated the interval (nth subject) from the sampling list then randomly picked the first respondent from the population. The researcher interviewed ten respondents per day, hence the interval was derived by dividing the expected number of patients in a day by ten. For example if the clinic had scheduled 70 ART refill appointments in a particular day, then the interval was derived by dividing 70 by 10, hence the interval for that day was 7. The starting point was randomly selected from any number between 1 and 7. For example if the researcher selects 5 as the starting point, the members of the sample during that day was 5, 12, 19, 26, 33, 40, 47, 54, 61 and 68.

Pumwani clinic uses an electronic register whereby patients' appointment dates are well recorded as well as the purpose of the appointment visit. That is either, medical review, blood sample collection or ART refill. Most of the times the medical review and the blood collection are scheduled to coincide with the ART refill appointment apart from a situation whereby the patient needs close follow up either due to side effects, opportunistic infection or poor adherence.

The well organized appointment schedules allowed the researcher to know in advance which patients were expected to visit the clinic for ART refill on a particular day. This on the other hand was appropriate in selecting the patients to be interviewed during the data collection period.

#### 3.3.2.2. In-depth interviews

Additional data was obtained through in-depth interviews administered to key informants who in this case were ART patients and Health Care Workers at the Pumwani Clinic. The participants were chosen because of their prior experience either as patients taking

antiretroviral medications or health care workers with experience in HIV care and management. Hence they were deemed as having knowledge and experience in matters related to antiretroviral medications.

The in-depth interviews involve use of semi-structured, open ended interview guides which give room for probing and clarifications. In-depth interviews with the patients provided information regarding constraints to optimal adherence, perceived benefits of ART, views and experiences of ART, brief history of diagnosis and treatment, any adherence issues encountered since initiation on ART and possible solutions. The interviewer also probed the respondents regarding acceptance of HIV status, disclosure of HIV status, gender and financial constraints including food insecurity to find out whether these factors can be associated with sub-optimal adherence.

In-depth interviews with the key informants provides information regarding factors that may lead to sub-optimal adherence, strategies put in place by the health care facility to help patients adhere to treatment and recommendations on ways of dealing with the factors leading to sub-optimal adherence. All interviews were recorded using a digital audio recorder and transcribed. A semi-structured interview guide was used to collect this data.

The advantage of the in-depth interviews is that they are able to derive in-depth, detailed and informative descriptions of factors that affect adherence to antiretroviral medications which will compliment the data collected from the survey interviews enabling a holistic understanding of the topic.

#### 3.3.2.2. 1. Sampling technique

The non-probability sampling method was implemented in the qualitative research utilizing purposive sampling technique in order to select 22 patients on ART for the semi-structured interviews and 9 health care providers for the focus group discussions. These participants were chosen because of their prior experience either as patients taking antiretroviral medications or health care providers with experience in HIV Care and

Treatment. Hence they were deemed as having knowledge and experience in matters related to antiretroviral medications.

Patients were eligible to participate if they had been taking antiretroviral medications for at least one month at the study clinic, were at least 18 years old and willing to participate in the study. Patients were purposively selected from the previous cohort that had participated in the survey interviews regarding factors influencing adherence to ART. 15 patients with pill count adherence level of 95% and above and 15 patients with pill count adherence level below 95% were selected to participate in the study. These patients were given a phone call informing them that they had been selected to participate in the study. Of the 30 patients called to come to the clinic in order to participate in the study, 4 could not be reached on the phone, 3 were not available to participate due to work commitment, 1 declined to participate and 22 were available to participate in the interviews and gave written informed consent.

All health care providers working at the study clinic were eligible to participate since they were all involved in care and treatment of people living with HIV/AIDS. Those who participated included 5 nurses, 2 nurse/counselors, 1 clinical officer and 1 social worker. The nurse in charge of the clinic was informed about the study and was asked to identify and refer at least eight staff to participate in the study. The identified staff members were informed about the study and written informed consent was obtained.

The researcher collected the data personally and interviews with the patients took an average of 20 minutes each, the focus group discussion took about an hour and in depth interviews with the two health care providers took about 20 minutes. The qualitative assessments followed the semi-structured interview and focus group discussion guides. The interview guide for the patients was designed to provide information regarding constraints to optimal adherence, perceived benefits of ART, views and experiences on ART, brief history of diagnosis and treatment, any adherence issues encountered since initiation on ART and possible solutions.

The interviewer also probed the respondents regarding acceptance of HIV status, disclosure of HIV status, and financial constraints to find out whether these factors can be associated with sub-optimal adherence. The interview guide for the health care providers was designed to provide information regarding factors that may lead to sub-optimal adherence, strategies put in place by the health care providers to help patients adhere to treatment and recommendations on ways of dealing with the factors leading to sub-optimal adherence.

### 3.4. Data analysis

The data collected was both quantitative and qualitative in nature. Quantitative data cleaning, entry and analysis employed Statistical Package for Social Sciences Programme (SPSS). Respondents' adherence levels were calculated using pharmacy pill counts. Chi-square tests and multivariate logistic regression were used to determine predicting factors. Frequencies were used to analyze patient socio-demographic factors, ART service delivery environment, patient social behavioral factors and knowledge and perception of HIV and ART. Bivariate analysis of the association of the hypothesized predictor variables was performed on all variables and those variables that were found to have a significant relationship with adherence were used in performing multivariate logistic regression. Significance level of 95% was used to determine the strength of association between the variables, hence p-values less than 0.05 were deemed to exhibit significant association to ART adherence.

Qualitative data was analyzed using NVIVO 8. All interviews were audio recorded using a digital recorder and transcribed. Transcribed interviews were coded using NVIVO 8. Coding was done in two phases, the first phase included development of a code book which was done deductively by developing codes from the interview guide and research question. The second phase of coding was done inductively by developing additional codes from the transcripts. Patients' and health care providers' transcripts were coded and analyzed separately and then compared for common themes. Representative, verbatim quotes were selected to illustrate key findings.

### 3.5. Ethical considerations and ethics approval

The study participants were given an opportunity to voluntarily participate in the study after being taken through the informed consent process. The study received ethics approval from the KNH-UON Ethics Review Committee.

#### 3.5.1. Informed Consent

All the eligible study participants, both the patients and the healthcare workers were approached by the researcher, given information about the study and those willing to participate were given an informed consent form to read and sign indicating that they had understood the purpose of the study, the study procedures and had willingly agreed to participate in the study.

# CHAPTER FOUR

# DATA ANALYSIS AND PRESENTATION

This chapter presents a general overview of the study findings. The main variables discussed are proportion of respondents who adhered to ART, socio-demographic factors, patient-related factors, ART service delivery environment and regimen related factors such as pill burden, knowledge and perception regarding HIV and ART, and facilitators and barriers to adherence.

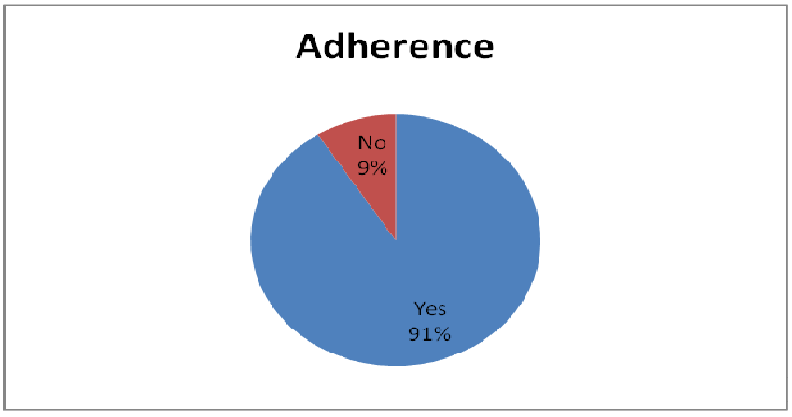
## 4.1. Proportion of the respondents who adhered to ART

This was a cross sectional survey which measured adherence to antiretroviral medications using pharmacy pill counts whereby the healthcare worker counts the remaining pills from the previously prescribed drugs during clinic visit using the formula below:

$$\frac{\text{Intended pills (\ \ ) – Remaining pills (\ \ )}}{\text{Intended pills (\ \ )}} \times 100 = \_\_\_\_\_\%$$

The researcher adopted this formula from the Pumwani clinic's standard of measuring adherence; hence pill count data was extracted from the respondents' clinical charts. Out of the 277 respondents interviewed, the researcher managed to retrieve pill count data from 260 respondents of which 91% (238) had perfect adherence levels between 95 and 100%, indicating the level of adherence in this study was high.

**Figure 2: Distribution of respondents by adherence**



Initial adherence findings in Sub-Saharan Africa indicate that 77% of patients on ART achieved adequate adherence (Mills et al., 2006). Other studies in Africa have found varying adherence levels. A study in Ethiopia found adherence rates of 94.3% using self reported dose adherence (Amberbir et al., 2008) another study conducted in Ethiopia, Kenya, Rwanda and Uganda indicated 72.6% self reported perfect adherence (Ross-Degnan et al., 2010) and in Kenya a study conducted in Nyeri, Karatina and Thika found adherence levels of 74% using (VAS) visual analogue scale (Wanjohi, 2009) while a study conducted in Nairobi found adherence rates of 82% using CASE (Center for Adherence Support Evaluation) which asked patients three questions regarding difficulty taking medications, days in a week that a patient missed medication and the last time that a patient missed medication (Wakibi et al., 2011).

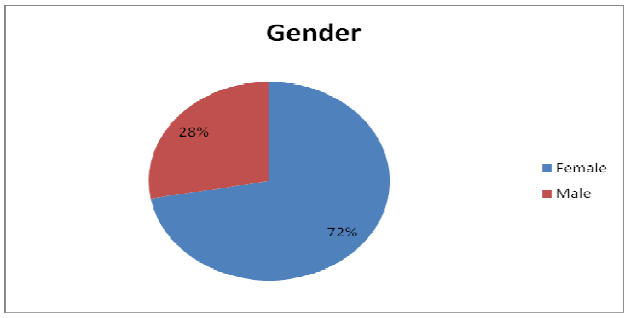
### 4.2. Socio-demographic characteristics

This section will describe study findings on socio-demographics characteristics such as age, gender, marital status, level of income, level of education, and duration on ART.

#### 4.2.1. Gender

Gender has always played a prominent part in the discussion of HIV/AIDS and the study sought to establish the gender distribution of the respondents. Out of 277 respondents interviewed, 72% (200) were female and 28% (77) were male. This indicates that there are more women than men seeking HIV care and treatment at the Pumwani clinic, at the same time this reflects the discrepancy in infection rates between men and women. In sub-Saharan Africa, women account for nearly 60 % of those living with HIV indicating that women are more susceptible to HIV due to their biological nature, economic, social and cultural pressures (UNAIDS, 2009).

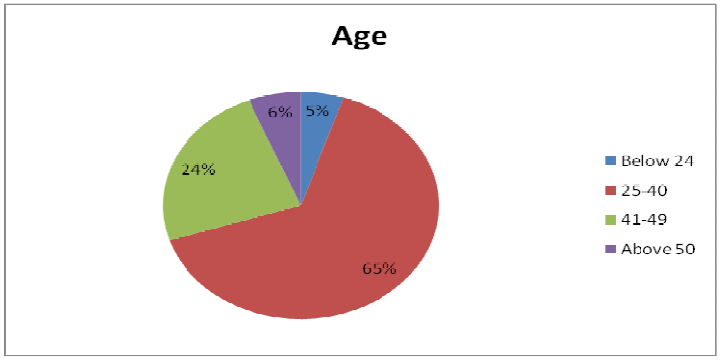
**Figure 3: Distribution of respondents by gender**




### 4.2.2. Age

The median age of respondents interviewed was 35 years with the youngest respondent being 19 years old and the oldest being 66 years old. Most (94%) of the participants were aged between 18 years and 49 years old which indicate that a large number of young people attend the clinic compared to the older generation. This age group compared to the older generation is expected to be more sexually active and economically productive hence the risk of contracting HIV, the likelihood of testing for HIV and accessing care and treatment services.

**Figure 4: Distribution of respondents by age**

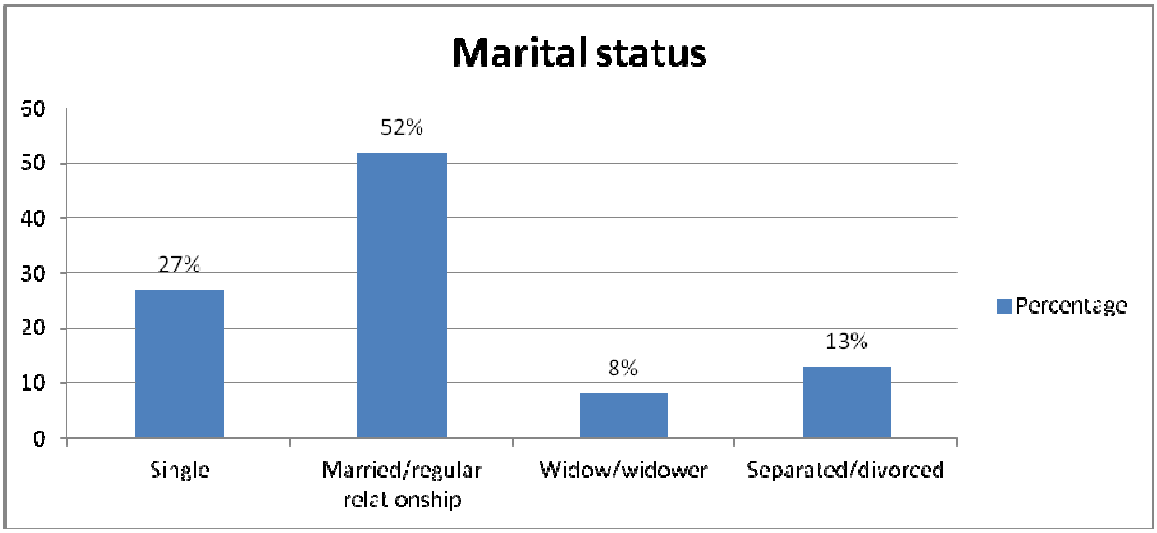



### 4.2.3. Marital Status

The study determined the marital status of the respondents since it is generally expected that social support from spouses or partners would positively influence adherence. In this study, 52% (143) of the participants were married or in a regular partnership. 27% (76)

were single, 8% (21) were widows or widowers and 13% (37) had separated or divorced. This indicates that marital status can be an important risk factor for HIV infection in the Kenyan setting. This observation is consistent with the 2007 Kenya AIDS Indicator Survey which indicates that Kenyans currently married or living with a partner are more likely to be HIV infected (7.6% HIV prevalence) than those who have never been married or lived with a partner (3.3% HIV prevalence) (NASCOP, 2009).

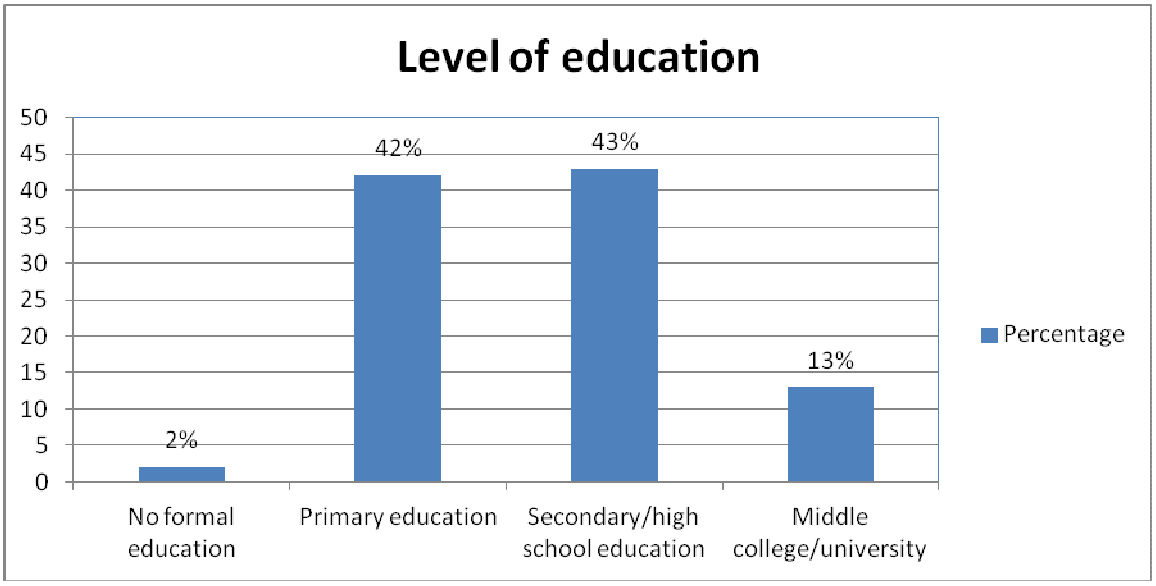
**Figure 5: Distribution of respondents by marital status**




### 4.2.4. Level of education

Majority of the respondents' highest level of education was either primary or secondary school education with 42% (115) of the respondents highest level of education attained being primary school education, 43% (119) secondary education, 13% (37) middle level college or university education and 2% (6) had not received any formal education. This indicates that those with higher education levels may have lower HIV infection rates than those with lower education levels.

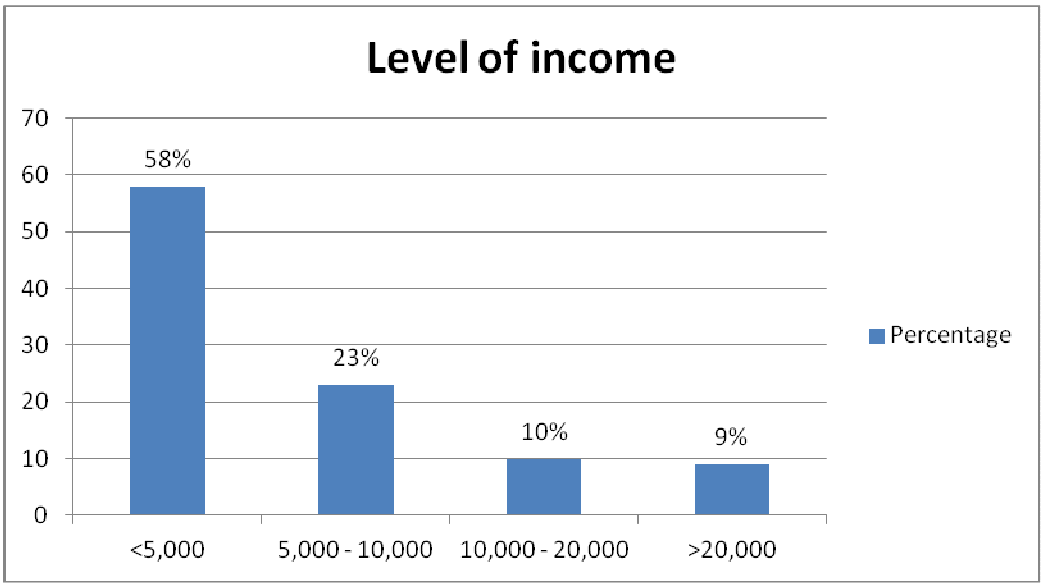
**Figure 6: Distribution of respondents by level of education**




### 4.2.5. Income

In this study 57% (157) of the respondents earn an estimate of 5,000 Shillings and below per month, 23% (64) earn an income between 5,001 and 10,000 Shillings, 10% (28) earn an income between 10,001 and 20,000 Shillings while 9% (24) earn an income above 20,000 Kenya Shillings. One respondent declined to respond to the question. Given that the Pumwani clinic is situated in Nairobi Eastlands a low socio-economic area, it was expected that most respondents would be in the low income category, that is, casual employment, self employment or unemployed. This explains why almost 60% of the respondents earn an income of 5,000 shillings and below per month.

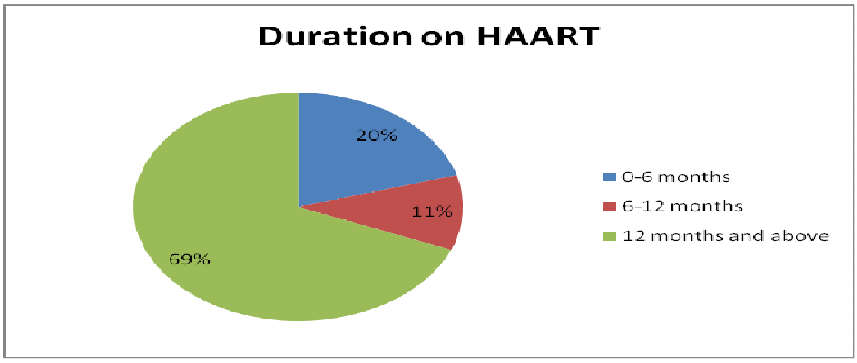
**Figure 7: Distribution of respondents by income**




### 4.2.6. Duration on HAART

This study explored the duration on that respondents have been on HAART based on the assumption that patients who had been taking ART for duration of less than six months would be less adherent due to challenges such as side effects which are usually more prominent for patients newly initiating ART compared to those that have been longer on the therapy. Majority of the study participants had been on HAART for duration of 12 months and above, that is, 69% (188), 20% (56) had been on HAART for 6 months and below and 11% (29) had been on HAART for more than 6 months but not more than 12 months.

**Figure 8: Distribution of respondents by duration on HAART**



### 4.3. Patient social behavioural environment

A patient's behaviour is critical in determining treatment outcomes. The decision to disclosure one's HIV seropositive status, miss clinic appointments, use of memory aids, treatment assistants, alternative medicine, alcohol and other substances could either negatively or positively impact adherence to ART. Table 1 shows behavioural characteristics of the respondents who participated in this study.

#### 4.3.1. Disclosure

In this study there were high levels of HIV disclosure, with 89% (248) having disclosed their HIV status. The high level of HIV status disclosure was also reflected in the key informant interviews with patients whereby all patients interviewed indicated that they had disclosed their HIV status to someone close to them and trustworthy enough not to reveal their status to others. A 43 years old female respondent described how she disclosed her status to the daughter:

> *"She (daughter) asked me about it and I disclosed and she encouraged me to continue taking drugs"- (Female patient, 34 years old)*

A 41 years old male respondent discussed the outcome of having disclosed his status:

> *"But after I did (disclose status) they welcomed me and have been very supportive, even my brother is the one who was reminding me about clinic appointments and even escorting me to the clinic"- (Male patient, 41 years old)*

The main motivation for disclosure was so as to receive support from the disclosed persons when sick or taking medications.

#### 4.3.2. Treatment assistant

HIV programs have been encouraging patients to acquire a treatment buddy to support them in HIV care and treatment especially during the early initial months after being initiated on ART. Although it is not mandatory for patients attending Pumwani clinic to

obtain a treatment assistant before ART initiation, a third (36%) of the respondents in this study had treatment assistants. One of the recommendations made by three health care workers interviewed on strategies to improve adherence and retention at the clinic was the use of treatment buddies.

> **Interviewer:** ***What are some of the strategies that can be used to encourage patient retention and adherence?***
>
> Female Nurse Counselor in charge of patient literacy: *"Maybe we can use treatment buddies to remind patients about appointments and also for treatment follow up… "*
>
> Male Nurse Counselor in charge of prevention among HIV positive patients: *"Also encouraging patients to have treatment buddies especially those who tend to forget a lot that can come in handy…because that can greatly influence how the person adheres to their treatment"*
>
> Overall Nurse in charge of the clinic: *"We could apply this thing of getting buddy system, to at least get a patient a partner to assist, sometimes the patient may be very sick and incapacitated for a while they need someone to give them or remind them to take ARVs"*

It seems the use of treatment assistant or buddy can be explored among patients as a strategy to improve adherence and give support to patients when they are unwell.

### 4.3.3. Use of memory aids

Patients with difficulties in remembering doses may be encouraged to use memory aids/reminder tools to boost adherence to medications. In this study, 40% (111) of the respondents were either using or had ever used memory aids such as alarms, beepers and medication diaries to support them in adhering to the medications. Memory aids can come in handy in enhancing adherence especially among patients with poor adherence due to forgetfulness or just being busy. A 38 years old female respondent acknowledges forgetting to take her drugs due to stress from social economic problems:

> *"It's not that I had issues with the drugs it's me who used to forget to take drugs…I was stressed because of my children school issues; I had not paid my rent and didn't have any job. I was stressed for three months; it was too much that I came here with serious ulcer problems"- (Female patient, 38 years old)*

One of the mechanisms used by the respondents in this study when confronted with such a challenge was use of memory aids such as an alarm as elaborated below by a 41 years old male respondent:

> *"There is also a time I remembered to take the drugs when it was already too late, but that was happening when I started taking the drugs. Right now if you check my watch when the alarm goes off it means it's time to take the drugs and then I set it for the evening drugs"- (Male patient, 41 years old)*

This shows that memory aids can be used as a mechanism of boosting adherence level among patients with poor adherence.

### 4.3.4. Alternative medicine

Use of herbal remedies for boosting the immune system and faith healing methods for overall well-being and stress relief is not an uncommon practice among people living with HIV (Peltzer et al., 2010). This practice can be associated with ART non-adherence due to drug interactions which can alter the effectiveness of ART and where patients consider themselves cured and cease or withdraw from treatment.

In this study, very few respondents (4%) reported using herbal medicine and faith healing (6%). The reason for the low reported numbers may be due to respondents' reluctance to disclose their use of alternative medicine as the clinicians advice against use of herbal medicine and encourage patients to continue taking ARVs despite seeking spiritual practices.

### 4.3.5. Missed appointments

Missed appointments can negatively impact adherence to ART due to failure by patients to refill drug prescriptions and lack of continuous monitoring by the health providers. In this study, a third (33%) of the respondents reported having ever missed a clinic appointment. The main reason cited for missing appointments were having travelled out of town, being busy and forgetfulness. Other reasons included work schedule, having extra drugs and lack of transport to the clinic.

### 4.3.6. Alcohol and substance abuse

A meta-analysis of 40 studies which assessed the influence of alcohol on adherence to ART indicate that individuals who drink alcohol are approximately 50% less likely to adhere to antiretroviral medications than those who abstain from alcohol (Hendershot et al., 2009). Since alcohol and substance abuse may limit people's ability to adhere to antiretroviral medications, the study sought to find out if respondents were using alcohol or any other substance. Only 18% (49) of the respondents reported using alcohol or any other substance within the last one month

During the key informant interviews, respondents pointed out that use of alcohol and or any other substances might negatively influence adherence to ART as described below by two female respondents aged 31 and 34 years old.

> *"They (alcohol and substance abuse) might interact with the drugs and reduce the efficacy of the medication" – (Female patient, 31 years old)*
>
> *"…alcohol weakens the immune system and when you take alcohol you are not in your right judgment and so are chances of forgetting. It has happened to me every time I go out and drink I forget and from time immemorial I know that they don't work with drugs"- (Female patient, 34 years old)*

This shows that the respondents understand that antiretroviral medications interact with alcohol and other substances and as a result patients may develop weakened immune system and may skip prescribed pills due to forgetfulness. This may explain why over three quarters of the patients did not take alcohol or other substance in the last one month.

**Table 1: Distribution of patients' social behavioral factors**

| Characteristics | Frequency | Percent |
|---|---|---|
| **Disclosure of HIV status (n=277)** | | |
| Yes | 248 | 89.5 |
| No | 29 | 10.5 |
| Total | 277 | 100.0 |
| **Have a treatment Assistant (n=277)** | | |
| Yes | 100 | 36.1 |
| No | 177 | 63.9 |
| Total | 277 | 100.0 |
| **Use memory aids (n=277)** | | |
| Yes | 111 | 40.1 |
| No | 166 | 59.9 |
| Total | 277 | 100.0 |
| **Use herbal medication (n=276)** | | |
| Yes | 12 | 4.4 |
| No | 264 | 95.6 |
| Total | 277 | 100.0 |
| **Use faith healing (n=276)** | | |
| Yes | 17 | 6.2 |
| No | 259 | 93.8 |
| Total | 276 | 100.0 |
| **Used alcohol and or any substance in the last one month (n=277)** | | |
| Yes | 49 | 17.7 |
| No | 228 | 82.3 |
| Total | 277 | 100.0 |
| **Ever missed an appointment (n=276)** | | |
| Yes | 91 | 33.0 |
| No | 185 | 67.0 |
| Total | 277 | 100.0 |

### 4.4. ART service delivery environment and perceived pill burden

Factors such as distance to the clinic, time taken to queue before a patient is attended by a clinician, time missed from work or home to attend the clinic, satisfactory services, trust in health care providers and pill burden could positively or negatively impact adherence to ART.

Table 2 below shows the distribution of respondents by these variables. In terms of distance, 57% (157) of the participants lived within 10 kilometers radius of the clinic, 74% (205) used public transport to the clinic, 72% (199) paid less than 100 Kenyan shillings to and from the clinic, 55% (152) miss up to half a day of work to attend clinic. Most of the participants, that is, 63% (173) take less than an hour queuing before being attended by a health care provider during clinic appointments, 73% (203) rated the services delivered at the clinic as good, and 99% (274) indicated that they trust the health care providers.

Pill burden in terms of the number of pills per dose and the number of doses per day may affect adherence due to fatigue from the amount of pills and the frequency of the doses. The need to fit these drugs in once daily schedule in addition to drug toxicity and side effects may influence an individual's motivation and ability to adhere to the medication. Additional data collected during key informant interviews with the healthcare providers indicate that pill burden is not only a result of the cocktail of three antiretroviral medications but also from prophylaxis medications given to HIV positive patients such as Septrin and Multivitamin and drug used to treat any opportunistic infections that patients may have. One of the clinical officers at the clinic reiterates that:

> *"Pill burden can affect adherence since most HIV positive patients are on Septrin and multivitamin so when you are started on ARVs you are given three more drugs and when you come with OIs (opportunistic infections) you are added more drugs". – (Clinical Officer)*

In this study, 44% of the respondents took 2 pills per day, 16% took 3 pills per day, 14% took 4 pills per day, 10% took 5 pills per day, 15% took 6 pills per day and 1% took either one or seven pills per day. This indicates that majority of the respondents were on

the fixed dose combination which means that they were taking one pill in the morning and another in the evening which comprised of the three cocktail drugs.

**Table 2: Distribution of respondents by ART service delivery environment**

| Characteristics | Frequency | Percent |
|---|---|---|
| **Distance (n=277)** | | |
| <10 km | 157 | 56.7 |
| 10-20 km | 86 | 31.0 |
| >20km | 34 | 12.3 |
| Total | 277 | 100.0 |
| **Mode of transport (n-277)** | | |
| Walking | 68 | 24.5 |
| Public transport | 205 | 74.0 |
| Cycling | 2 | .7 |
| Driving | 2 | .7 |
| Total | 277 | 100.0 |
| **Time missed from work (n-274)** | | |
| Less than two hours | 41 | 14.9 |
| Three hours | 49 | 18 |
| Up to half a day | 152 | 55.4 |
| Whole day | 28 | 10.2 |
| More than one day | 4 | 1.5 |
| Total | 277 | 100.0 |
| **Queuing time (n-277)** | | |
| less than one hour | 173 | 62.5 |
| Up to two hours | 76 | 27.4 |
| Up to three hours | 23 | 8.3 |
| Up to half a day | 4 | 1.4 |
| More than half a day | 1 | .4 |
| Total | 277 | 100.0 |
| **Rate services (n-277)** | | |
| Very good | 50 | 18.1 |
| Good | 203 | 73.3 |
| Average | 23 | 8.3 |
| Poor | 1 | .4 |
| Total | 277 | 100.0 |

| | | |
|---|---|---|
| **Trust HCWs (n-277)** | | |
| Yes | 274 | 98.9 |
| No | 3 | 1.1 |
| Total | 277 | 100.0 |
| | | |
| **Pill taken per day (n-277)** | | |
| 1 | 2 | .7 |
| 2 | 122 | 44.0 |
| 3 | 45 | 16.2 |
| 4 | 38 | 13.7 |
| 5 | 27 | 9.7 |
| 6 | 42 | 15.2 |
| 7 | 1 | .4 |
| Total | 277 | 100.0 |

### 4.5. Knowledge and perceptions on HIV and ART

Knowledge and perceptions regarding HIV and ART can influence adherence to ART. Misconceptions such as ARV medications are not a lifelong therapy and that patients can stop medications once they feel better could negatively impact adherence to medications. Various variables were used by to assess the respondents' knowledge and perceptions on HIV and ART. Most of the participants (65%) were aware that HIV is different from AIDS and 92.8% (256) reported someone could have HIV but show no signs of AIDS. Almost all the respondents, that is, 98% (272) were aware that HIV can be controlled by ART though 28% (10) reported that HIV can be cured by ART. 95% (264) were aware that treatment on ART is a lifelong therapy and 19% (53) were not aware or not sure that ART can cause side effects. Majority of the respondents, that is, 96% (263) believe that ART reduces HIV related morbidity and mortality, though 25% (68) were not aware or not sure that ART can prevent mother to child transmission and 56% (154) did not know or were not sure that ART can be used as a prophylaxis to prevent transmission of HIV after rape. A look at the effect of alcohol and substance abuse and how they can impair judgment revealed that 95% (262) of the respondents believe that alcohol and substance abuse can affect practicing safer sex. Majority of the respondents, that is, 98% (272) also

indicated that it is necessary to use condoms even if both partners are living with HIV (see table 3).

During the key informant interviews, the respondent were asked to generally state what they knew about HIV and ARV medications. In terms of HIV knowledge most of the respondents mentioned the need to prevent HIV transmission and re-infection by using condoms. They also stated that HIV is manageable and that it weakens the body's immunity hence needs to be controlled by using antiretroviral medications. Some of the respondents also mentioned that there are benefits of HIV testing and especially knowing one's HIV status early. In terms of ART knowledge, majority of the respondents pointed out that adhering well to the medication can reduce replication of the virus, reduce drug resistance, and boost the body's immune system hence reduce opportunistic infections and prolong one's life. A female respondent aged 44 years old captures all these aspects in the excerpt below.

> *"It is important to take your medication well so that you can boost your immune system as we are always told every time you don't use your medicine consistently they lose their power… your body could reject them so it's important to be consistent so that you can live longer on the same medicine, to avoid drug resistance"- (Female patient, 44 years old)*

This indicates that the respondents have high health literacy level in regard to HIV and ART knowledge. This may further explain why this study had high adherence levels with 92% of the respondents achieving near-perfect adherence levels of 95% and above.

**Table 3: Distribution of respondents by knowledge and perception on HIV and ART**

| Characteristic | Response | Frequency | Percent |
|---|---|---|---|
| **Being infected with HIV is different from having AIDS (n=277)** | Yes | 181 | 65.3 |
| | No | 68 | 24.6 |
| | Don't know/not sure | 28 | 10.1 |
| | Total | 277 | 100.0 |
| **One can have HIV and not have AIDS symptoms (n=276)** | Yes | 256 | 92.7 |
| | No | 11 | 4.0 |
| | Don't know/not sure | 9 | 3.3 |
| | Total | 276 | 100.0 |
| **HIV positive individuals show signs of HIV infection right away (n=271)** | Yes | 33 | 12.2 |
| | No | 232 | 85.6 |
| | Don't know/not sure | 6 | 2.2 |
| | Total | 271 | 100.0 |
| **Alcohol and drugs can impair judgement and motivation to practice safer sex (n=276)** | Yes | 262 | 94.9 |
| | No | 12 | 4.4 |
| | Don't know/not sure | 2 | .7 |
| | Total | 276 | 100.0 |
| **It is necessary to use condoms if both partners are HIV positive (n=277)** | Yes | 272 | 98.2 |
| | No | 2 | .7 |
| | Don’t know/not sure | 3 | 1.1 |
| | Total | 277 | 100.0 |
| **How long should one take ARVs? (n=277)** | Lifelong | 264 | 95.3 |
| | Till ones health improves | 1 | .4 |
| | Don’t know | 12 | 4.3 |
| | Total | 277 | 100.0 |

| | | | |
|---|---|---|---|
| **ARV can prevent mother to child transmission (n=276)** | Yes | 208 | 75.4 |
| | No | 39 | 14.1 |
| | Don't know/not sure | 29 | 10.5 |
| | Total | 276 | 100.0 |
| **ARV can prevent risk of HIV transmission after rape (n=273)** | Yes | 119 | 43.6 |
| | No | 131 | 48.0 |
| | Don't know/not sure | 23 | 8.4 |
| | Total | 273 | 100.0 |
| **HIV can be controlled by ART (n=276)** | Yes | 272 | 98.6 |
| | No | 2 | .7 |
| | Don't know/not sure | 2 | .7 |
| | Total | 276 | 100.0 |
| **HIV can be cured by ART (n=277)** | Yes | 28 | 10.1 |
| | No | 240 | 86.6 |
| | Don't know/not sure | 9 | 3.2 |
| | Total | 277 | 100.0 |
| **ART reduces HIV related morbidity (n=275)** | Yes | 263 | 95.6 |
| | No | 6 | 2.2 |
| | Don't know/not sure | 6 | 2.2 |
| | Total | 275 | 100.0 |
| **ART reduces HIV related mortality(n=277)** | Yes | 265 | 95.7 |
| | No | 8 | 2.9 |
| | Don't know/not sure | 4 | 1.4 |
| | Total | 277 | 100.0 |

| | | | |
|---|---|---|---|
| **ART can cause side effects(n=276)** | | | |
| | Yes | 223 | 80.8 |
| | No | 50 | 18.1 |
| | Don't know/not sure | 3 | 1.1 |
| | Total | 276 | 100.0 |

### 4.6. Facilitators and barriers to ART adherence

This section outlines facilitators and barriers to adherence to antiretroviral medications. Two variables were identified as facilitators to adherence during the analysis of the survey questionnaire, that is, level of income and use of memory aids. In addition, other facilitators of adherence were identified using key informant interviews and they are meant to give an in-depth understanding of what motivated the respondents to adhere to ART given the high adherence levels observed in this study. On the other hand, the barriers to adherence give an in-depth understanding of why 8% of the respondents did not adhere well to the drugs and also reasons why adherent patients may sometimes fail to adhere to the medications from time to time.

#### 4.6.1. Facilitators of Adherence

##### 4.6.1.1. Level of income

Table 4 shows the results of the bivariate analysis. Only two variables were found to be significantly associated with adherence to antiretroviral medication, that is, memory aid with p-value 0.008 and income with p-value of 0.01. To facilitate easier interpretation of the bivariate results multivariate logistic regression analysis was conducted and the two variables were also found to have a significant relationship with adherence (see table 5). Respondents earning an income of 20,000 Kenyan shillings and above were four times more likely to adhere to ART (p-value 0.023, 95% CI and odds ratio 4.093). This could be because of the ability to meet expenses such as transport to the clinic, food and shelter leading to a better way of dealing with economic problems that can negatively affect adherence.

**Table 4: Bivariate analysis**

| Bivariate analysis | Adhered | | Not adhered | | P-Value | Level of significance | Degree of freedom | Test | Value of chi-square |
|---|---|---|---|---|---|---|---|---|---|
| **Income (n=256)** | | | | | | | | | |
| <=5,000 | 137 | 91.3 | 13 | 8.7 | 0.01 | 0.05 | 1 | Chi-square | 6.96 |
| 5,001-20,000 | 82 | 96.5 | 3 | 3.5 | | | | | |
| >20,000 | 16 | 76.2 | 5 | 23.8 | | | | | |
| **Memory Aids (n=260)** | | | | | | | | | |
| Yes | 101 | 97.1 | 3 | 2.9 | 0.008 | 0.05 | 2 | Chi-square | 9.30 |
| No | 137 | 87.8 | 19 | 12.2 | | | | | |

It is widely acknowledged that individual level of income has great influence on one's individual health with increasing income level being related to improvement in health and health outcomes. Differences in level of income generally make a bigger difference for health among the low income groups since increase in level of income among the high income groups may not produce significant improvement in health (Braveman & Egerter, 2008). While money on its own does not produce good health, level of income is widely acknowledged to be related to the social and economic opportunities to which a person may be exposed to and these may in effect affect an individual's health and health outcomes (Adler & Rehkopf, 2008). In this study income may have served as a buffer against everyday stress that may be associated with inadequate financial support.

Income may affect health at the household level, community and national level. At the house hold level, in the low to middle-income countries it has been shown that those with more financial wealth tend to use health services more frequently and to a greater degree than those with less financial wealth and that they use more modern health providers than the traditional practitioners (Castro-Leal et al., 1999). The poor may also be disadvantaged due to the number of children a family has, poor diet, lack of water and

poor sanitary practices such as washing hands and disposal of feces. At the community level, the population size can have an effect on the availability of facilities, accessibility of facility is also a factor that should be considered due to distance and transport issues, quality of care for the facilities providing services to the poor tend to be low. For instance these facilities tend to be poorly stocked with drugs and medicines and the attitude of the healthcare providers may not be similar to those offering services in more affluent populations.

At the national level, there may be inequality and inequity in health utilization across countries. Revenue collection and financing of health program may have an impact on health outcomes. For instance access to health insurance coverage may affect an individual's health seeking behavior in terms of the timeliness in seeking health care and accessibility of prescribed drugs. African health systems face a huge financing deficit. Sub-Saharan Africa accounts for 22 % of the total global disease burden and more than 68% of the people living with HIV yet the region is home to 12% of the world population (Atim et al., 2008). During the 2001 Abuja meeting, African leaders committed to allocating 15 percent of total government spending to the health sector (African Summit on HIV/AIDS, tuberculosis and other related infectious diseases 2001), in addition the Commission for Macroeconomics and Health recommended that low income countries spending for health care should rise to UD$38 per person by 2015 (WHO, 2001) but only few countries have managed to reach these targets. In order to decrease the disease burden in the region the African governments need to bridge the financial gap and develop innovative mechanisms of financing the health sector. In the meantime most patients accessing medical services in Kenya have to pay for these services out of their pockets. This system makes it difficult for the poor to access medical services.

Although ART is free in most public health facilities in developing nations, level of income may affect adherence to ART. For instance lack of food and difficulty in meeting the cost associated to treatment such as transport and monthly consultation cost may influence a patient's ability to adhere to the medications (Skovdal et al., 2011). A study that examined determinants of ART adherence in sub-Saharan Africa using ethnographic

research methods at HIV comprehensive care facilities in Nigeria, Tanzania and Uganda indicate that individuals taking ART routinely overcome economic obstacles to ART adherence through a number of deliberate strategies aimed at prioritizing adherence such as borrowing and "begging" transport funds, making "impossible choices" to allocate resources in favor of treatment and "doing without"(Ware et al., 2009) . These patients applied the theory of planned behavior, specifically the perception on subjective norm to behavior to enhance adherence to medication. They prioritized adherence through resources and help received from significant others. By doing so they also promoted good will on the part of the significant others who always help them with material support.

#### 4.6.1.2. Use of memory aids

Table 5 shows that in this study respondents using memory aids were five times more likely to adhere to ART (p-value 0.016, 95% CI and odds ratio 4.864). This shows that memory aids can be used as a mechanism of boosting adherence levels among patients with poor adherence.

**Table 5: Multivariate logistic regression analysis on income and use of memory aids**

| **Multivariate Analysis** | | | | | | | **95% C.I. for EXP(B)** | |
|---|---|---|---|---|---|---|---|---|
| | B | S.E. | Wald | df | **P-Value** | **O.R** | **Lower** | **Upper** |
| **Memory Aids** | | | | | | | | |
| No | Reference | | | | | 1 | | |
| Yes | 1.582 | 0.654 | 5.852 | 1 | 0.016 | 4.864 | 1.35 | 17.526 |
| | | | | | | | | |
| **Income** | | | | | | | | |
| < KES 5,000 | Reference | | | | | 1 | | |
| 5,001-10,000 | -0.944 | 0.781 | 1.459 | 1 | 0.227 | 0.389 | 0.084 | 1.8 |
| 10,001-20,000 | -0.712 | 1.07 | 0.442 | 1 | 0.506 | 0.491 | 0.06 | 3.998 |
| >KShs 20,000 | 1.409 | 0.619 | 5.179 | 1 | 0.023 | 4.093 | 1.216 | 13.78 |
| | | | | | | | | |
| **Income** | | | 8.612 | 3 | 0.035 | | | |
| < KES 5,000 | -1.409 | 0.619 | 5.179 | 1 | 0.023 | 0.244 | 0.073 | 0.822 |
| 5,001-10,000 | -2.353 | 0.905 | 6.758 | 1 | 0.009 | 0.095 | 0.016 | 0.561 |
| 10,001-20,000 | -2.121 | 1.162 | 3.335 | 1 | 0.068 | 0.12 | 0.012 | 1.168 |
| >KES 20,000 | Reference | | | | | 1 | | |

During the key informant interviews with the patients, 6 out of the 22 patients reported using memory aids such as alarms to remind them to take their medications. Patients reported that whenever they encountered challenges such as forgetting to take medications or simply being busy they opted to use reminder tools such as alarms or calendars to improve adherence to medications.

Use of memory aids or reminder tools such as medication/pill diaries and alarm devices, have been employed in the treatment of chronic illnesses to encourage patients to attend follow-up appointments, refill prescriptions, follow physician instructions, use correct doses or timing and continue treatment for the full duration. Non–adherence to medication could be because of challenges such as being busy or forgetting to take medications, work commitment and economic pressures leading to missed refill appointments due to fear of losing wages and side effects of the medications.

Non-adherence to medication can either be intentional because of fear and negative images of medicines or non-intentional (Britten, 1994). Reminder tools or memory aids target non-intentional adherence behavior and aim at prompting pill taking. Literature on use of reminder tools to improve adherence has been inconsistent. A study conducted in China indicated that non-adherence among patients with no reminder tools was 4.22 greater than those who used some reminder methods (Wang & Wu, 2007). These findings are consistent with findings reported in this paper that adherence among patients who used reminder tools is 5 times greater than those who did not use reminder tools. A recent meta-analysis that systematically reviewed published randomized controlled trials of reminder interventions to assist patient adherence to prescribed medications showed that patients in the reminder groups averaged 11.9% higher adherence than those in the control groups (Fenerty et al., 2012).

A study conducted in Kenya compared the effects of counseling and alarm device on adherence to ART and virologic outcomes and showed despite the fact that the alarm devices were widely accepted by participants they did not have any beneficial effect on adherence or viral failure. Those participants who received intensive counseling were

59% less likely to experience viral failure and 29% less likely to experience poor adherence compare to those who received no counseling (Chung et al., 2011).

The inconsistencies in the findings regarding usage of reminder tools for adherence can be attributed to the design of the interventions, the wide array of reminder tools used and the methods used to measure adherence.

The rest of the facilitators and barriers to adherence discussed below were identified using key informant interviews with 22 patients and 9 health care providers

#### 4.6.1.3. Improved health status

More than half the patients interviewed during the key informant interviews were motivated to test for HIV because of poor health status hence suspected they could be living with HIV. After testing HIV positive all patients are usually referred to a HIV comprehensive care clinic. Most (15) of the patients interviewed went to the referred clinic within one week after testing HIV positive and were initiated into HAART almost immediately, meaning that their immune system was low (a CD4 count below 250) hence when interviewed regarding facilitators of adherence to ARV medications most expressed the need to boost their immune system through improved CD4 as one of the reasons as to why they ensured that they did not miss the prescribed medications.

Boosting of the immune system was also closely related to improved health status as patients expressed that after starting to take the ARV medications they do not get sick as often as they used to and that the fear of being sick motivated them to adherence to medications. A female respondent aged 35 years explains what motivates her to adhere to ART.

> *"I don't have those counter infections I used to have, so I am motivated if I stop taking these drugs may be it will happen again considering where I work and the scare of TB so I have to adhere...I wouldn't want to get TB, I know I have to boost my immunity so I have to take my drugs faithfully". – (Female patient, 35 years old)*

The patients also expressed that the desire for prolonged life span acted as a motivator of adherence to the medication. The excerpt below shows the association between desire for prolonged life span, improved health status and motivation to adhere to drugs.

> *"I want to live longer, if I miss the drugs I will die, it's not that I will not die but if I take them according to the doctor's instruction they are helping me. I usually don't have any health problems since I started taking them". – (Female patient, 31 years old)*

The health care providers on the other hand stated that they counsel the patients to adhere well to the ARVs so that they can boost the immune system and avoid being sick.

> *"You see if you talk to a patient and tell them that as long as you are started on ARVs and take the drugs well the CD4s will start going up and when the CD4s go up and when the patient does not getting sick they are motivated to continue taking the medication". – (Clinical Officer)*

When patients were started on ART they experienced improved health status which motivated them to adhere to the medications.

#### 4.6.1.4. Having dreams to accomplish

When patients were asked what benefits they had received from the ARVs most of them mentioned that they don't feel sick as often as they used to and that their immune system had been boosted. Other benefits included feeling normal due to improved health status, weight gain, increase in strength and ability to work so that they don't have to rely on others for provision of basic needs.

The improved health status, ability to perform normal work and continue with normal life encouraged patients to go back to their dreams and obligations. The following respondent explains why adherence to ART is important to him.

> *"I have seen a group of men of my age around my village, there are those guys who didn't know when this thing happened to come around, they are all under six feet now, but me I am still alive and kicking and bringing up my children. So that's why I have to keep it up very much, because the children of those guys are*

*still suffering. There is no way anyone can bring up your children the way you would. So that's why I have to keep up with that moral to ensure that my last born is stable so that in case I might go they can help each other." – (Male patient, 47 years old)*

The obligation of not only taking care of one's nuclear family but also the extended family acted as a motivator to adhere to drugs in order to fulfill these responsibilities as described by the following patient who acts as the provider and protector of the extended family.

*"I have told you that I have lost so many brothers so their wives and the family rely on me for protection…most of the responsibilities of my dead brothers are on my shoulders. If I was to die soon I don't know who I would transfer my responsibilities to, so that one, at least I should carry the cross of our family to a level that can be understood." – (Male patient, 40 years old)*

A 30 year old male respondent also relates the desire to be a successful person in the society with motivation to adherence.

*"I know that I have a future so I would like to see my future because according to what I was told about ARVs you can live to your old ripe age when taking them so I would like to see my future as much as I could have seen it when I didn't have the virus in the body. I want to live it just like any other ordinary person because of the very many things that are ahead of me and I want to be a successful person in the society…"- (Male patient, 30 years old)*

This shows that having responsibilities and dreams to accomplish was a motivator to adherence to ART.

#### 4.6.1.5. Faith in the drugs

Some of the patients were motivated to adhere well to the drugs because of the faith they had bestowed on the drugs due to their ability to improve health status and prolong life. These resulted in patients making drug taking a daily routine in their life. Patients referred to drugs as life and as their food/diet. The respondent below explains how he has made taking of drugs part of his daily routine.

*"I am used to my medication they are like breakfast, lunch, if you miss lunch you feel hungry so it's something like that. If I get late somewhere or time passes I feel so bad, even if I am on the vehicle my mind tells me that there is something that I have not done." – (Male patient, 45 years old)*

The female respondent below refers to ARV medications as her life.

*"It's because I know that these drugs give me life. The place where I am at I know that there is nothing as important to me like these drugs. If I mess a little bit that would be the end of my life and there is no other way." – (Female patient, 38 years old)*

This shows that belief in the efficacy of the drugs encourages adherent behavior. This is because that belief makes it easier for patients to fit the drugs into their lifestyle.

#### 4.6.1.6. Support from others

Support from treatment buddies, support group, health care providers were also deemed as motivators of adherence especially during the early stages after starting to take ARV medications. Half of the patients interviewed stated that they had or were attending support group meetings which gave them strength and encouraged them to continue taking drugs. This was mainly because they felt they were not alone and that testimonies and experiences from those that have been taking drugs for a longer time acted as a motivator to adherence. The following respondent explains how support group meetings have been helpful to him.

*"I meet people who got infected earlier on and those who have been infected recently. So people talk about their challenges and get advice from those who have had a similar challenge, so it's like learning all the time, you educate yourself every time."- (Male patient, 45 years old)*

All the clients interviewed had disclosed their HIV status to someone close to them. The main reasons for disclosure were so that they could receive support from the disclosed persons when sick or taking medications and that the persons disclosed were trustworthy and close to the patients. Most patients reported receiving support from the people disclosed to by being encouraged or reminded to take the medications, being reminded

about clinic appointments and being escorted to the clinic for appointments or health education. Two patients also reported receiving spiritual support from those disclosed to. The healthcare providers also reported that counseling and support groups helped improve adherence. Health care providers reported encouraging all patients to go through adherence counseling to ensure they are ready for ART initiation. After initiation, if patients have adherence levels below 95% they are referred to the counselor who seeks to find out the issues underlying poor adherence and how these issues can be resolved.

### 4.6.2. Barriers to adherence

This section outlines some of the barriers to adherence identified by both patients and health care providers. Patients were asked to state some of the challenges they had encountered since they were initiated on antiretroviral medications while the health care providers were asked to state some of the factors that may lead to sub-optimal adherence.

Most patients cited forgetfulness and side effects as a challenge in taking medications followed by the fear that someone might see them taking the medications, change of lifestyle, traveling and lack of food.

The health care providers mentioned drug holidays, traveling, lack of understanding/commitment, faith healing, and factors within the clinical setting as barriers to adherence. The interviewer also probed the health care providers regarding their views on how adherence is affected by issues such as disclosure, stigma, gender and cost of health care.

#### 4.6.2.1. Side effects

Side effects to antiretroviral medications especially during the early stages into initiation to the medications were cited as a challenge to taking antiretroviral medications by patients.

The following respondent narrates his experience with Anemia after being initiated into ART.

> *"First they started helping me but I got side effects. After two and a half months I got anemia due to side effects of AZT. I was admitted at Coptic Hospital…the medication was changed and the doctor told me to stay for sometimes without taking ARVs, I stayed for around one month, I was just using Septrin and Multivitamin…" – (Male patient, 40 years old)*

Other side effects mentioned include: rashes, nausea and vomiting, fat redistribution within the body, numbness and/or stabbing pain in the toes or fingers and drowsiness.

#### 4.6.2.2. Forgetfulness

Forgetfulness due to stress, being unwell and most of the time just simply forgetting was also cited as a barrier to adherence. The following male respondent describes his experience with forgetfulness.

> *"You can't find a time that you didn't forget to take pills. Sometimes you remember when you are already on your way out so the next time you have to carry the drugs with you"- (Male patient, 41 years old)*

A female respondent relates her forgetfulness with being preoccupied with her new born baby.

> *"Like the first time I was introduced to them I was sure that I would be taking but by the end of it all when we went to count we realized I had not taken so many tablets and another time was when I got my baby because I was so possessed with the baby more than myself I forgot myself I think every time I would give her medicine I would think I have also taken so in those two occasions there was an alarm. I was too busy"- (Female patient, 44 years old)*

Forgetfulness can also be huge barrier to adherence if patients do not learn how to fit drug taking into their lifestyle.

#### 4.6.2.3. Fear of disclosure and stigma

Patients mentioned challenges with adherence to medications due to not disclosing their HIV status to others. They discussed the fear that other people might see them taking drugs hence had to find a secluded place where they could take drugs. This fear led some to repackage their drugs in different drug containers that do not bear ARVs labels. This on the other hand led to confusion with patients taking one drug regimen and not the other since some drugs look alike in terms of color and shape of the pills.

The following patient explains why he repackages his drugs

> *"…May be I got confused because I had removed the drugs from the container because I take the medication while in the car. I can't use the container because it is noisy and can give me stigma and I don't want stigma in my life" – (Male patient, 50 years old)*

The female patient below also explains why she repackages the drugs.

> *"I remove them from the container and put them in another polythene paper for drugs, because I don't want other people to know the drugs I take…that's why I hide the drugs"-( Female patient, 41 years old)*

Another respondent describes why she doesn't take her medications on time.

> *"When I am at a family gathering and the time arrives when you have to take your drugs and you are wondering what do you do and you don't want people asking what is this that you are taking so that a challenge"- (Female patient, 34 years old)*

This shows how non disclosure of HIV status can lead of non adherence due to fear of being stigmatized.

#### 4.6.2.4. Change of lifestyle

Three patients mentioned change of lifestyle as a barrier to adherence to the medications, mainly because of the requirement of lifelong commitment to the medication regimens.

A female respondent describes being fatigued by the drugs due to the requirement to take the drugs daily.

> *"Sometimes you feel discouraged, I take the drugs daily, day in day out there is no day that I don't take the drugs, so it reaches a time you feel like you are not created for that life" – (Female patient, 37 years old)*

This was reiterated by the clinicians who reported that sometimes the patients get fatigue from taking the medications daily so some go on drug holiday to break off the routine.

#### 4.6.2.5. Travelling

Patients reported challenges taking drugs when they had travelled. For example, one patient reported missing drugs for one month because she had travelled upcountry and did not know where to go for ARV refill. Another patient reported missing drugs for 4 days because she confused her drugs and could not go to back to the clinic for instructions on how to take her drugs since she had travelled out of town.

The clinicians also reported that people who are always traveling for example the truck drivers or those who travel upcountry or out of town make a good number of poor adherers at the clinic.

#### 4.6.2.6. Lack of commitment

When patients did not understand the benefits of adhering to the medications especially right after they had been started on drugs, they lacked commitment to the drugs making it difficult for them to follow the drug intake instructions given by the clinicians.

> *"Initially I had not put them in mind but after getting to know the importance of drugs I put them in the mind. I was not following the instructions as such but after being done the CD4 test after three months that's when I realized that these drugs are helpful and I started taking the drugs well"- (Female patient, 41 years old)*

Lack of commitment due to not understanding the benefits of the drugs was also reported by the clinicians as one of the reasons why patients may not be able to take their medications well.

#### 4.6.2.7. Lack of food

One respondent reported not adhering well to the medication due to lack of food

> *"None apart from sometimes you find that you don't have food and you are supposed to take medication so when you take them they make you weak so you are better off not taking the drugs" – (Female patient, 37 years old)*

The healthcare providers also reported that in some cases cost may affect adherence for patients who lack food.

#### 4.6.2.8. Other factors mentioned by the clinicians

Other barriers to adherence mentioned by the clinicians included patients **feeling they are fine**, **faith healing, pill burden** and **factors within the clinic set up** such as attitude of the health workers which can lead to inability to ensure one communicates properly and passes clear information to the patients.

The interviewer also probed the health care providers regarding some of the factors that can affect perfect adherence to medications such as gender, disclosure, stigma and cost of health care. The health care workers reported that **disclosure** often affects adherence because if one has not disclosed their HIV status they often have to hide their medication making it difficult to adhere well to the treatment compared to someone who has disclosed their status and has been accepted by those disclosed to because in such a situation those disclosed to often support the patients by reminding them to take their medications.

During the focus group discussions the health care providers concurred that **gender** may be a factor that affects adherence though they did not concur on which gender adheres better than the other. Some felt that women adhere more than men because of the responsibility of taking care of children hence that's a motivating factor for adherence while others felt that men adhere more than women because the HIV status disclosure to the partner is higher in men than women and also that women have more responsibilities at home and this may lead to sub optimal adherence.

On **cost** being a factor that affects adherence the health care providers reported that the Pumwani clinic caters for the cost of most of the conditions related to HIV by providing free outpatient services. The only costs they don't cater for are inpatient services. The healthcare providers also reported that in some cases cost may affect adherence for patients who lack transport to the clinic or food.

### 4.7. Mechanisms of dealing with the barriers to adherence

Table 6 below gives an outlines of the mechanisms identified by both patients and the health care providers for dealing with the barriers to adherence.

**Table 6: Mechanisms of dealing with identified barriers to adherence**

| **Mechanisms of dealing with the barriers to adherence to medications** | | |
|---|---|---|
| **Barrier** | **Patients views** | **Health care providers views** |
| Side effects | o Contact healthcare providers either through phone call or visit the healthcare facility | o Change the regimen if the side effect is severe<br>o Health education and adherence counseling<br>o Reassurance |
| Forgetfulness | o Change time that the medication is taken to fit daily routine<br>o Reminder tools such as alarm, treatment buddy<br>o Do own pill count<br>o Fixed dose combination | o Reminder tools such as alarm or treatment buddy<br>o Encourage patient to do own pill count<br>o Give short clinic appointment to facilitate close monitoring and frequent counseling |
| Fear of disclosure and stigma | o Take medications in a secluded place<br>o Put drugs in a re-sealable small paper bags<br>o Put drugs in a more accessible place in case you have visitor and fear they might see one taking drugs<br>o Discipline and commitment to take drugs no matter the situation because of the benefits one gets from the drugs | o Prevention with positives program which encourages disclosure among partners together with their households, adherence to the medications among other things |
| Change of lifestyle | o Discipline and commitment to the drugs because of their efficacy<br>o Acceptance of one's HIV status and acknowledgement of benefits one gets from the drugs | Health education and counseling regarding the benefits of adherence |
| Travelling | o Carry all drugs instead of a few for the stipulated time one is expected to be away<br>o Collect drugs from other health facilities in case the visit is longer than expected | Encourage the patients to carry all the drugs while traveling and to collect drugs from other facilities in case they stay longer than the expected time |
| Lack of commitment | o Discipline and commitment to the drugs because of their efficacy<br>o Find time for drug refills and clinic appointments | o Support group meetings<br>o Treatment buddy<br>o Repeat adherence counseling |
| Lack of food | o Support group meetings from other organizations such as church where part of the support given is food supply | o Nutrition counseling |
| Feeling fine and healed | | o Treatment buddies<br>o Support group meetings |
| Faith healing | | o Continuous counseling<br>o Support group meetings |
| Pill burden | | o Fixed dose combination |
| Factors within the clinic set up | | o Continuous monitoring of patients through pill counts, self-reported adherence, CD4 count<br>o Improve on communication skills and positive attitude towards the patients |

# CHAPTER FIVE

# DISCUSSION OF THE FINDINGS, CONCLUSION AND RECOMMENDATIONS

This chapter involves a discussion of the major findings based on the problem statement and study objectives, conclusion and recommendations based on the study findings.

## 5.1. Discussion

This study aimed at understanding factors that influence both optimal and sub-optimal adherence in patients on ART in a Kenyan setting. As stated in Chapter one, the objectives of the study were to: 1) determine the adherence levels among the PLHIV; 2) determine the predictors of adherence; 3) determine the knowledge, attitude and behavior on adherence to ARVs among the PLHIV; 4) identify and explore barriers and motivators of adherence to antiretroviral medications and 5) recommend possible interventions to improve ART adherence

### 5.1.1. Adherence levels among the PLWH

Perfect adherence levels of 95% and above are desirable in ensuring positive health outcomes and treatment success among patients taking ART. Adherence using pharmacy pill count in this study was high. 91% (228) of the patients on ART achieved perfect adherence (<95%). These adherence rates are comparable to adherence rates of 94% in Ethiopia (Amberbir et al., 2008), and 92% in Nairobi, Kenya (Mungai et al., 2012) but inconsistent with the findings in Central Kenya (74%) (Wanjohi, 2009), Nairobi, Kenya, (82%) (Wakibi et al., 2011) and initial sub-Saharan Africa adherence rates of 77% (Mills et al., 2006). The inconsistency with other findings from Kenya can be attributed to the differences in adherence measurement methodologies. This study utilized pill counts for assessing adherence while Wanjohi utilized Visual Analogue Scale and Wakibi et al. utilized Center for Adherence Support Evaluation (CASE).

### 5.1.2. Determine the knowledge, attitude and perception (KAP) on adherence to ARVs among the PLWHAs

In this study no association was found between KAP and adherence to ART. Patients' knowledge, attitude and perception of HIV and ART were high. This could be attributed to the intensive adherence counseling before and after ART initiation at the Pumwani HIV comprehensive care clinic. Study findings suggest that health literacy is a predictor of HIV knowledge (Hicks et al., 2006) and HIV treatment adherence (Kalichman et al., 2008).

Patients being initiated on ART at the Pumwani clinic undergo three adherence counseling sessions: The first session is an interactive group session where the patients are taken through HIV education which entails history and basic knowledge on HIV including the meaning of CD4+ (level of body's immunity) laboratory results, opportunistic infections, antiretroviral medications and importance of adherence as well as good nutrition. After this session patients are given an appointment for adherence two session. This session includes a one on one individualized counseling and education session focusing on treatment using ARV medications in terms of duration, adherence, side effects, HIV prevention and any issues that the patient might have. Patients understanding of the information given during session one and two is also ascertained using a standard checklist which helps the clinician to assess the patient's readiness for ART initiation. For those patients with poor understanding of information, ART initiation is delayed and the adherence two session is rescheduled to ensure the patient is ready for the treatment. Once patients successfully undergo adherence two counseling session they are given an appointment to attend adherence three session which addresses side effects and reinforces what was discussed in adherence one and two. At pill pick-up appointment patient's adherence level is assessed and anyone with an adherence level below 95% is referred to a counselor for adherence counseling.

A study in Soweto, South Africa also found that patients' knowledge, attitude, behavior and perception on HIV/AIDS and ART was high though it didn't assess how this knowledge, attitude, behavior and perception predict ART adherence (Nachega et al., 2005)

### 5.1.3. Identify and explore facilitators and barriers to adherence to antiretroviral medications

This study assessed whether social demographic characteristics, knowledge, attitude and perceptions on HIV, ART delivery environment and other factors such as disclosure, alternative medicine and memory aids influenced adherence to ART. Upon conducting bivariate analysis only two factors were significantly associated with perfect adherence, that is, income and use of memory aids. When multivariate analysis was done on these two variables they were both significantly associated with perfect adherence. Patients earning an income of 20,000 Kenyan shillings and above were four times more likely to adhere to ART (p-value 0.023 and odds ratio 4.093) while patients using memory aids were five times more likely to adhere to ART (p-value 0.016 and odds ratio 4.864).

Findings on whether socio-demographic factors influence adherence are inconsistent. In this study only income had a significant association to adherence. A study in Nairobi, Kenya found that gender, age, marital status, education level and income did not have significant association to adherence (Wakibi et al., 2011). Another study in Nyeri, Kenya found that age, occupation and education were significantly associated with adherence while gender and marital status were not (Wanjohi, 2009). A study in Botswana found that age, distance to the facility, cost of transport and duration on treatment did not indicate any significant association to adherence to ART though there was a significant association between employment status and adherence (Hardon et al., 2006).

Regarding ART delivery environment and patient social behavioral factors this study found memory aids to be the only factor associated with adherence. The study findings in regard to memory aids being a predictor of adherence is consistent with a study in Ethiopia which found that use of memory aids and social support were associated with perfect adherence (Amberbir et al., 2008). The findings are inconsistent with a study in Kenya which found use of alarm device to have no effect on adherence to ART (Chung et al., 2011).

In the qualitative assessment of motivators and barriers to adherence to ART using key informant interviews with the patients and health care providers five factors emerged to explain optimal adherence: 1) Improved health status after ART initiation; 2) having dreams to accomplish and meet family obligations; 3) faith in the drugs (patients referred to drugs as food or life) resulting in making drug taking part of the daily routine; 4) support from others such as treatment buddies, support groups, health care providers, and 5) use of reminder tools. Eleven factors emerged to explain barriers to adherence: 1) Forgetfulness; 2) side effects; 3) fear of stigma; 4) change of lifestyle; 5) mobility; 6) lack of commitment; 7) lack of food; 8) patients feeling they are not sick; 9) faith healing, 10) pill burden; and 11) factors within the clinic set up .

These study findings on facilitators of adherence are consistent with findings from Tanzania which identified improvements in health after starting ART, need to meet family obligations, routinizing pill taking, material and emotional support from others and trust in the advice and instructions given by health care providers as facilitators of adherence (Watt et al., 2009). Another study in Zambia identified feeling better, prospects of living longer, family support, information about ART, support for income generating activities, disclosure of HIV status, prayers and transport support as facilitators of adherence (Sanjobo et al., 2008).

Although financial constraints such as lack of transportation cost to the clinic for ART refill was not mentioned as a barrier to adherence to ART, other studies have found transportation cost as a barrier to adherence (Tuller et al., 2010). The Zambian study also identified lack of communication and information about ART, inadequate time during consultations, lack of follow up and counseling, lack of confidentiality in the treatment centers and lack of nutritional support as barriers to ART adherence (Sanjobo et al., 2008). Contrary to the study findings from Zambia, the health workers interviewed in this study emphasized the importance of giving adequate information regarding HIV and ART and intensive counseling to ensure patients are well prepared before being initiated on HAART.

## 5.2. Conclusion

Level of adherence using pharmacy pill count was high, with 91% of the patients on ART achieving perfect adherence (<95%).

Bivariate analysis of the hypothesized predictor variables was conducted to find out if there was any association between these variables and adherence. Two variables were found to be significant as predictors of adherence to antiretroviral medications, that is, memory aid with p-value of 0.008 and income with p-value of 0.05. Further analysis that employed multivariate logistic regression was used to further illustrate the relationship between these variables and adherence. Both variables were found to have a significant relationship with adherence.

Patients earning an income of 20,000 Kenyan shillings and above were four times more likely to adhere to ART (p-value 0.023 and odds ratio 4.093) while patients using memory aids were five times more likely to adhere to ART (p-value 0.016 and odds ratio 4.864)

No association was found between adherence to ART and knowledge, attitude and perceptions on HIV and ART. Patients' knowledge, attitude and perception of HIV and ART were high and this may be attributed to the intensive adherence counseling before and after patients are initiated on ART.

There are various barriers and motivators of adherence and although adherence was high in this study, it can further be improved by employing individualized strategies that target challenges that each patient may be encountering. Patients and health care providers interviewed in this study recommended possible interventions to deal with the identified barriers to adherence to ART. The health care providers recommended emphasis on the prevention with the positive programs (which helps HIV infected individuals to reduce the risk of transmitting HIV to others and also puts an emphasis on adherence to antiretroviral medications and disclosure of HIV status especially to sexual partners, support group meetings, use of treatment buddies, fixed dose combination, improvement on communication skills and attitude towards patients and continuous monitoring of

patients through CD4 count test, pill count, self reported adherence and repeated adherence counseling.

The patients recommended the following interventions to improve adherence to ART: contacting health care providers in case they have any side effects either through phone call or visiting the health facility, changing the time one takes medication to fit into their daily schedule, use of reminder tools such as alarm, use of treatment buddies, doing own pill count, takings medications in a secluded place in case of presence of someone they have not disclosed HIV status to, carrying all their ARV medications in case they are travelling and discipline and commitment to the ARV medications.

### 5.3. Recommendations

Adherence to treatment requires team work, the patients, health care providers and policy makers are all important and active participants. This section will give recommendations at the individual, institutional and policy levels.

At the individual level, patients need to assess themselves in order to find out what motivates them to adhere and also some of the barriers that make them non-adherent to medication. This will help patients form positive attitude towards adherence and deal with the barriers encountered. In this study, patients were asked to describe some of the challenges they have encountered while taking medications and mechanisms that they can use to improve adherence and these mechanisms have been outlined in table 6. A good example is that when some patients realized that they had challenges with dose timing and pill intake they put an alarm on their phones to prompt them to take their medications at specific times of the day.

At the facility/institution level, the health care providers have the obligation to inform the patients fully and help them understand HIV, ART adherence, benefits and risks of adhering or not adhering to the treatment plan, importance of good nutrition, disclosure, partner testing and usage of condoms among other details that are outlined during early and repeated counseling phases. The health care providers also need to help patients

adhere to the decided upon plan which must be individualized since each patient has their own motivators or barriers to adherence. Strategies that can encourage patients to improve on disclosure of HIV status, acquire treatment assistants and join support groups either at the facility or at the community level. These strategies should be developed by the facilities in consideration of the factors deemed important by patients and health care providers too. Continuous adherence monitoring plan is also key and plays a big role in measuring health outcomes and developing personalized adherence strategies.

At the policy level, the policy makers should review empirical research focusing on interventions to improve adherence to ART and come up with interventions that are specific to the Kenyan population. At the national level, the policy makers should also design mechanisms of collecting adherence data from all the facilities in the country and make this data available for use by the health care providers and researchers. There is lack of data on rates of adherence to ART not just in Kenya but in most of the countries in Africa and an effective adherence monitoring and documentation system needs to be set up. The only data available on adherence is by various studies targeting different parts of the country.

There is need for systematic review of adherence studies conducted in Kenya to answer the following research questions?

1. What are the estimates of antiretroviral therapy adherence in Kenya?
2. What are the most feasible and cost effective interventions to improve antiretroviral therapy adherence in Kenya?

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## APPENDICES

### Appendix 1: Informed Consent for quantitative research with patients on ARVs

### Study Title: Factors influencing Adherence to Antiretroviral Medications among Patients Living with HIV/AIDS in Kenya

This informed consent will be read to you, please feel free to ask for further clarification in any issue that you may not understand. Your participation in this study is voluntary; you can withdraw from the study at any time and failure to participate in this study will not affect the services you receive at this clinic.

Part 1: Information sheet

Introduction

This study is being conducted by Sarah Karanja as part of her master's degree programme at the University of Nairobi and it will explore factors influencing the uptake of antiretroviral medications among patients living with HIV/AIDS and also recommend possible interventions to improve ART adherence.

You are being asked to participate in this study because you are an adult on antiretroviral medications at Pumwani clinic which has been selected as a study site. We are providing information to you about this study and would like to invite you to be part of this survey.

If you accept to participate, this interview which will take about 30 minutes. The administered questionnaire will determine your knowledge, attitude, behavior and perception on HIV and antiretroviral medications, it will explore barriers and motivators to adherence and measure your adherence levels using self recall on how many pills you have missed the previous day, week and month and using pill count in the last one month. Your participation is entirely voluntary, and your decision to participate or not to participate will not affect the services you receive at this clinic

There may be no direct benefit for you in participating in this research study. Though you will be able to discuss with the interviewer any adherence issues that you may have and the interviewer will provide you with the necessary counseling required.

There is also no known risk in participating in this study, though you might feel that your time has been inconvenienced. Some questions may upset some individuals, particularly concerning social or psychological aspects of having HIV. If you are upset you may choose to skip those questions, or stop participation and seek support from the counselors at the clinic. You have a right not to answer any question that you choose not to answer. This will not interfere with the services that you receive in this clinic and neither will it interfere with your participation in other parts of this interview.

Any information that you provide to us will be kept confidential. Information collected from you will be stored securely and only the researchers will have access to it. Also we will not use your name on the questionnaire; we will use an identification number that will be assigned to you.
After data collection we will prepare a report which might be shared in conferences and publications but this report will not identify you in any way. Your confidentiality in participating in this research study is completely assured.

There will be no compensation of any kind due to participation in this research study.

If you have any questions after you have been interviewed you may contact Sarah Karanja on 0722395490.

Part 2: Certificate of consent

I have read the informed consent, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I consent voluntarily to participate as a participant in this research

| _____ | _____ | _____ |
|---|---|---|
| Name of participant | Date | Signature |

If illiterate

I have witnessed the accurate reading of the consent form to the potential participant and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely

| _____ | _____ | _____ |
|---|---|---|
| Name of participant | Date | Thumb print of participant |

| _____ | _____ | _____ |
|---|---|---|
| Name of the witness | Date | Signature |

Statement of the person taking consent

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked have been answered correctly and to the best of my ability. I also confirm that the individual has not been coerced into giving consent and the consent has been given freely and voluntarily.

| _____ | _____ | _____ |
|---|---|---|
| Name of the person taking consent | Date | Signature |

**Appendix 2: Informed Consent for semi-structured interviews with patients on ARV**

**Study Title: Factors influencing Adherence to Antiretroviral Medications among Patients Living with HIV/AIDS in Kenya**

The informed consent will be read to you, please feel free to ask for further clarification in any issue that you may not understand. Your participation in this study is voluntary; you can withdraw from the study at any time and failure to participate in this study will not affect the services you receive at this clinic.

Part 1: Information sheet

This study is being conducted by Sarah Karanja as part of her master's degree programme at the University of Nairobi and it will explore factors affecting the uptake of antiretroviral medications among patients living with HIV/AIDS and also identify and recommend possible interventions to improve ART adherence.

You are being asked to participate in this study because you are an adult on antiretroviral medications at Pumwani clinic which has been selected as a study site.

If you accept to participate in this study, this informal interview will take about 60 minutes. The interview will explore motivators and barriers to adherence to antiretroviral medications and also get your recommendation on possible interventions to improve ART adherence.

I will need to record the interview using an audio recorder in order to get all the information discussed with you accurately. The information recorded is confidential and no one except the researchers will access the information recorded. In order to further ensure confidentiality, I will not identify you by name on the recorder and the information recorded will be destroyed three years after completion of the study. No one else apart from the interviewer will be present unless you would like someone else to be there.

After data collection we will prepare a report which might be shared in conferences and publications but this report will not identify you in any way. Your confidentiality in participating in this research study is completely assured.

There may be no direct benefit for you in participating in this research study. Though you will be able to discuss with the interviewer any adherence issues that you may have and the interviewer will provide you with the necessary counseling required.

There is also no known risk in participating in this study, though you might feel that your time has been inconvenienced. Some questions may upset some individuals, particularly concerning social or emotional aspects of having HIV. If you are upset you may choose to skip those questions, or stop participation and seek support from the counselors at the clinic. You have a right not to answer any question that you choose not to answer. This

will not interfere with the services that you receive in this clinic and neither will it interfere with your participation in other parts of this interview.

There will be no compensation of any kind due to participation in this research study.

If you have any questions after you have been interviewed you may contact Sarah Karanja on 0722395490.

Part 2: Certificate of consent

I have read the informed consent, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I consent voluntarily to participate as a participant in this research

| _____ | _____ | _____ |
|---|---|---|
| Name of participant | Date | Signature |

If illiterate

I have witnessed the accurate reading of the consent form to the potential participant and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely

| _____ | _____ | _____ |
|---|---|---|
| Name of participant | Date | Thumb print of participant |

| _____ | _____ | _____ |
|---|---|---|
| Name of the witness | Date | Signature |

Statement of the person taking consent

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent and the consent has been given freely and voluntarily.

| _____ | _____ | _____ |
|---|---|---|
| Name of the person taking consent | Date | Signature |

**Appendix 3: Informed Consent for semi-structured interviews with healthcare workers**

**Study Title: Factors influencing Adherence to Antiretroviral Medications among Patients Living with HIV/AIDS in Kenya**

This informed consent is for healthcare workers at University of Nairobi, Pumwani comprehensive care clinic. We are inviting you to participate in a research study which is reviewing adherence to antiretroviral medications.

Part 1: Information sheet

This study is being conducted by Sarah Karanja as part of her master's degree programme at the University of Nairobi and it will explore factors affecting the uptake of antiretroviral medications among patients living with HIV/AIDS and also identify and recommend possible interventions to improve ART adherence.

You are being asked to participate in this study because you work at the Pumwani clinic which has been selected as a study site and also have knowledge and experience in providing HIV Care and Management.

If you accept to participate, this interview will be conducted in English and will take approximately one hour. You will be asked questions related to factors that may lead to optimal and sub-optimal adherence, what strategies you have in place at the health care facility to promote adherence and what further possible interventions can be put in place to ensure patients adhere well to antiretroviral medications.

You will be required to give written informed consent indicating that you have understood the purpose of the research and that they are voluntarily willing to participate in the study. Your participation in this research is entirely

I will need to record the interview using an audio recorder in order to get all the information discussed with you accurately. The information recorded is confidential and no one except the researchers will access the information recorded.

There may be no direct benefit for you in participating in this research study. There is also no known risk in participating in this study. You have the right not to answer any question that you may choose not to answer.

Any information that you provide to us will be kept confidential. Information collected from you will be stored securely and only the researchers will have access to it.

After data collection we will prepare a report which might be shared in conferences and publications but this report will not identify you in any way. Your confidentiality in participating in this research study is completely assured.

There will be no compensation of any kind due to participation in this research study.
As previously stated, your participation in this study is voluntary. You have the right to refuse to participate or withdraw participation and this will not affect the treatment or services you receive at this clinic.

Who to contact

If you have any questions after you have been interviewed you may contact Sarah Karanja on 0722395490.

Part 2: Certificate of consent

I have read the informed consent. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I consent voluntarily to participate as a participant in this research

| _____ | _____ | _____ |
|---|---|---|
| Name of participant | Date | Signature |

Statement of the person taking consent

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent and the consent has been given freely and voluntarily.

| _____ | _____ | _____ |
|---|---|---|
| Name of the person taking consent | Date | Signature |

**Appendix 4: Survey Questionnaire**

**Study Title: Factors influencing Adherence to Antiretroviral Medications among Patients Living with HIV/AIDS in Kenya**

Enrollment #: _____ Clinic #._____ Date of Interview _____

*Section 1: Demographics*

1. Gender?
   1=Female
   2=Male

2. When were you born? _____ Calculated age
   1=18-30
   2=30-40
   3=40-50
   4=Above 60

3. Where do you live?
   1. District _____ 2. Division _____
   3. Location _____ 4. Village/Estate _____

4. What is your highest level of education?
   1= no formal education 2=Primary school education
   3=secondary/high school education 4= middle college or university

5. What is your marital status?
   1=single 2=married 3=other (specify) _____

6. What is your occupation? _____

   1= formally/regularly employed (specify) _____
   2= casually/part time employed (specify) _____
   3= self employed (specify) _____
   4= a student
   5= unemployed

8. What is your spouse's/partner's occupation?
   1= formally/regularly employed (specify) _____
   2= casually employed (specify) _____
   3= self employed (specify) _____
   4= a student
   5= unemployed
   6= don't know
   7= n/a (no spouse)

9. What is your average monthly income?
   1= 0-5000
   2= 5000-10000
   3=10000-20000
   4=20000 and above

10. What is your spouse's/partner's monthly income?
   1= 0-5000
   2= 5000-10000
   3=10000-20000
   4=20000 and above

11. How long have you been on antiretroviral medications?
   1= 0 – 6 months
   2= 6 – 12 months
   3= 12 months and above

*Section 2: ART service delivery environment*

12. What is the distance from your residence to the HIV comprehensive care clinic?
   1= 0-10 km  2= 10-20 km  3= 20-50 km
   4= 50-100 km  5= 100 km and above

13. What is your mode of transport to the clinic?
   1= walking  2= public transport
   3= cycling  4=driving
   5=other (specify) _____

14. On average how much fare do you pay to and from the clinic?
   1= 0-20  2= 20-100
   3= 100 – 200  4= 200 and above

15. What other expenses did you incur as a result of being HIV positive?
   1= Food
   2= Hospitalization (in patient)
   3= Treatment of Opportunistic Infections
   4= Other, Specify_____

16. If yes, a) on average how much do you incur per month?
   1= 0-5000  2= 5000-10000
   3= 10000 – 20000  4= 20000 and above

17. How much time do you miss from home or work on average to attend the clinic?
   1= less than two hour  2= up to half day
   3= whole day  4= more than one day

18. How long do you usually wait on the queue before being attended by healthcare worker?

1= less than one hour 2= up to two hours
3= up to three hours 4= up to half a day
5= more than half a day

19. How would you rate the services you receive at this clinic?

1=very good 2=good 3=average
4=poor 5=very poor

20. Do you feel you can trust the health care workers?

1=yes
2=no

21. Do you have privacy during consultation and counseling?

1=yes
2=no

22. If no, why?

_____

_____

*Section 3: Knowledge, attitude and perception on HIV and ART*

*In the questions below, please give a 'yes' or 'no' answer. This set of questions will assess your knowledge of HIV and antiretroviral drugs. Please feel free to give whatever answer that you find is appropriate.*

23. Being infected with HIV is different from having AIDS

1= Yes 0=No

24. One can have HIV positive and not have AIDS symptoms?

1= Yes 0=No

25. HIV positive individuals show signs of HIV infection right away?

1= Yes 0=No

26. Is it possible to cure HIV/AIDS?

1= Yes 0=No

27. Alcohol and drugs can impair judgment and motivation to practice safer sex?

1= Yes 0=No

28. Is it necessary to use condoms if both partners are HIV positive?
    1= Yes  0=No

29. How long should one take ARVs? _____
    1=Lifelong
    2=Till one's health improves
    3=Other_____

30. ARV can prevents mother to child transmission
    1= Yes  0=No

31. ARV can prevent risk of HIV transmission after rape
    1= Yes  0=No

32. HIV can be controlled by ART
    1= Yes  0=No

33. HIV can be cured by ART
    1= Yes  0=No

34. ART reduces HIV related morbidity
    1= Yes  0=No

35. ART reduces HIV related mortality
    1= Yes  0=No

36. Taking ARVs reduces disease progression
    1= Yes  0=No

37. Antiretroviral medications can cause side effects
    1= Yes  0=No

38. ART can reduce the risk of HIV transmission in the community
    1= Yes  0=No

*Section 4: Other factors*

39. In the last one month have you used alcohol and/ other substance?
    1= Yes  0=No

40. Do you use alternative medicine (herbal or faith healing)?
    Herbal  1= Yes  0=No
    Faith healing  1= Yes  0=No

41. Have you disclosed your status to someone else other than the HCWs?

1= Yes 0=No

42. If yes, who have you disclosed your HIV status to? _____

_____

43. If yes to question 41, give reasons for disclosure
1=Encouraged by health care workers
2=Fear of serious illness & thus need of support from friends & family
3=Sufficient trust in the individual confided in
4=other, specify_____

44. If no to question 41, give reasons for not disclosing
1=Status disclosure to others
2=Rejection
3=Spouse violence
4=Being perceived as unfaithful
5=Procrastination
6=other, specify_____

45. Do you feel stigmatized by other people because of your HIV status?
1= strongly agree
2=disagree
3=agree
4=strongly agree

46. In the last one week, have you felt depressed?
0=rarely or none of the time (<1 day)
1=some or a little of the time (1-2 days)
2=occasionally or a moderate amount of the time (3-4 days)
3=most or all of the time (5-7 days)

47. Do you have a treatment assistant (someone to remind you to take your ARV medications)?
1= Yes 0=No

48. Do you use any memory aids to remind you to take your ARV medication?
1= Yes 0=No

49. If yes, which memory aids do you use?
1=electronic devices (alarms, beeper)
2=medication diaries
3=other (specify)

50. Has any of the following ever made you skip/stop taking your ARV medication?

| | | | |
|---|---|---|---|
| a) | Side effects | 1=Yes | 0=No |
| b) | Felt better | 1=Yes | 0=No |
| c) | Felt ill | 1=Yes | 0=No |
| d) | Herbal medicine | 1=Yes | 0=No |
| e) | Faith healing | 1=Yes | 0=No |
| f) | Felt better | 1=Yes | 0=No |
| g) | Cost of transport | 1=Yes | 0=No |
| h) | Distance to the clinic | 1=Yes | 0=No |
| i) | Lack of food | 1=Yes | 0=No |
| j) | Pill burden | 1=Yes | 0=No |
| k) | Lack of support/care | 1=Yes | 0=No |
| l) | Hospitalized | 1=Yes | 0=No |
| m | Did not understand instructions | 1=Yes | 0=No |
| n) | Shared pills | 1=Yes | 0=No |
| o) | Alcohol/substance use | 1=Yes | 0=No |
| p) | Forgot/busy | 1=Yes | 0=No |
| q) | Did not want others to see | 1=Yes | 0=No |
| r) | Depressed | 1=Yes | 0=No |
| s) | Did not have pills with you | 1=Yes | 0=No |
| t) | Ran out of pills | 1=Yes | 0=No |

51. What is your ARV medication dosage?

1=one tablet twice a day
2= three tablets twice a day
3= other, specify_____

52. Have you ever missed a schedule appointment at the clinic?

1= Yes 0=No

53. If yes, what was the reason for missed appointment?

1= lack of transport to the clinic
2= forgot
3= had travelled out of town
4= could not get permission from work
5= busy
6= too sick
7= still had some drugs to take
8= other, specify _____

54. What benefits have you gained from using ARV drugs?

_____

_____

55. What do you perceive as your main motivation for your use of ARV medications?

_____

_____

56. What do you perceive as the main challenge to your use of ARV medications?

_____

_____

57. What do you think is the best way of dealing with this challenge?

_____

_____

*Section 6: Adherence*

58. In the last one month, how many ARV medication pills did you miss?

$$\frac{\text{Intended pills (\ \ ) – Missed pills (\ \ )}}{\text{Intended pills (\ \ )}} \times 100 = \_\_\_\_\_\%$$

*The response to the last questions pill count adherence will be extracted from the clinic adherence questionnaire after the participants have been to the pharmacy for ARV refill on the same day.*

59. Pill count

$$\frac{\text{Intended pills (\ \ ) – Remaining pills (\ \ )}}{\text{Intended pills (\ \ )}} \times 100 = \_\_\_\_\_\%$$

60. Reasons for missed pills

_____

_____

Interviewer's initials _____

**Appendix 6: Guide for semi-structured interview with patients on patients on ARV**

**Study Title: Factors influencing Adherence to Antiretroviral Medications among Patients Living with HIV/AIDS in Kenya**

Enrollment #: _____ Clinic #._____ Date of Interview _____

*Introduction of the study and consenting*

Background information of the participant

| | |
|---|---|
| Gender | |
| Age | |
| Level of education | |
| Marital status | |
| Occupation | |
| Average Income | |

**History of HIV diagnosis and treatment**

Please give me a brief history of HIV diagnosis and treatment (Probe for when first diagnosed, reasons for testing, acceptance of HIV status, when started on ARVs)

**Disclosure and stigma**

I would like us to discuss HIV disclosure and the stigma related. Have you disclosed your HIV status to anyone and what was the impact of this disclosure? (Probe for who disclosed to, reason for disclosing, reasons for not disclosing and whether they have been treated differently after disclosing their status).

**Knowledge about HIV and ART**

I would like you to tell me what you know about HIV (let the patient talk then you can probe for mode of transmission, protection and preventive behaviour)

Please also tell me what you know about ARVs (Let the patient talk then you can probe for perceived benefits of ART, importance of adherence)

**Adherence**

I would like you to tell me about the ARV medications you are taking and whether you are or have experienced any challenges in taking your medications. Please feel free to communicate with me and any information you give me is confidential.

Please tell me the name of the drugs you are currently taking, how many pills you take per day and the time which you take your pills.

Are there any other medications that you are taking? (Either prescribed by the doctor, over the counter drugs, traditional herbal medicine)

In the last one day, that is, yesterday, did you miss any pills? If so what was the reason for missed pills?

In the last one week did you miss any pills? If so what was the reason for missed pills?

In the last one month did you miss any pills? If so what was the reason for missed pills?

In the last one year did you miss any pills? If so what was the reason for missed pills?

Have you ever stopped taking your ARV medication for some time? If so what was the reason (Probe whether they were stopped by the clinician or they did it by themselves, also find out the reason for discontinuation. If they have never stopped taking ARV medication, find out if they have ever thought about if)

Have you had your ARV medications changed and if so what was the reason for regimen change?

Have you ever missed an appointment at this clinic? If so what was the reason for this?

Do you think that alcohol and or substance abuse has any effect on ARV medication (Probe to find out whether the patient uses alcohol or other substances)

Have you encountered any challenges that made you stop or feel like stopping to take ARV medication?

What do you think can be done to improve this situation?

What encourages you to take your ARV medication? (Also probe for reminder tools used to ensure adherence)

**Financial implication**

I would like to find out if you incur any costs as a result of being HIV positive and if so on average how much money you incur per month (Probe about travel cost, lost income due to coming to the clinic, cost of OI treatment)

Is there any question that you think is important and I have not asked you?

Do you have any questions?

Thanks for your participation.

**Appendix 7: Guide for semi-structured interviews with HCWs**

**Study Title: Factors influencing Adherence to Antiretroviral Medications among Patients Living with HIV/AIDS in Kenya**

Enrollment #: _____ Clinic #._____ Date of Interview _____

*Introduction of the study and consenting process*

**Background information on the HCW**

I will start by asking you some basic information about you.
What is your profession?
What specific training have you received in relation to HIV care and management?
How many years of experience do you have in the ART field?
What is your role in the ART program in this clinic?

**Adherence in general**

What is the ART initiation procedure in this facility? Which guidelines do you follow?

In general, how would you rate adherence levels in this clinic?
Probe whether extremely good, very good, good, fair or poor and reasons given
Probe for percentages and measures used to determine adherence levels and how they monitor adherence in the facility.

Please give me your opinion on the following issues;

- How does disclosure affect adherence to ART?
- How does stigma affect adherence?
- How does gender affect adherence to ART?
- How would you compare adherence between men and women?
- How does cost affect adherence to ART?

In regard to HIV care and treatment in this clinic, which costs are covered by the clinic and which ones are not? (Probe on lab tests, OI treatment and drugs, hospitalization)
How does a patient's education level affect adherence to ART?

**Clinic Appointments**
Do your patients keep clinic appointments? What percentage, what are the reasons given by those who do not keep appointment, do you give them an option of discussing the appointment scheduling? What mechanisms are in place in the clinic to ensure patients keep their appointments?

**Lost-to-follow-up and defaulter rates**

Which patients do you consider as defaulters and lost-to-follow up? What are the defaulter rate and the lost to follow up rate in this clinic? What mechanisms have been put in place to trace defaulters?

**Factors that affect adherence to ART**

From your experience what are some of the factors that affect adherence? (Probe for factors that may lead to both near perfect or poor adherence)

What are some of the strategies that can be put in place to ensure adherence to ART? (Probe for strategies being used at the facility to promote adherence to ART)

Is there any question that is relevant to adherence that I have not asked?

Thanks for your participation.

## Appendix 8: Ethics approval letter

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25th October 2010

Ref: KNH-ERC/ A/609

Sarah Karanja
Sociology Department
University of Nairobi

Dear Sarah

**Research proposal: "Barriers to Antiretroviral medications adherence among patients living with HIV/AIDS in Kenya" (P249/7/2010)**

This is to inform you that the KNH/UON-Ethics & Research Committee has reviewed and **approved** your above revised research proposal for the period 25th October 2010 to 24th October 2011.

You will be required to request for a renewal of the approval if you intend to continue with the study beyond the deadline given. Clearance for export of biological specimens must also be obtained from KNH/UON-Ethics & Research Committee for each batch.

On behalf of the Committee, I wish you a fruitful research and look forward to receiving a summary of the research findings upon completion of the study.

This information will form part of the data base that will be consulted in future when processing related research study so as to minimize chances of study duplication.

Yours sincerely

PROF A N GUANTAI
SECRETARY, KNH/UON-ERC

c.c. The Deputy Director CS, KNH
The HOD, Records, KNH
Supervisor: Prof. Charles Nzioka, UON